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In 1998, Harvard University and the Merck Company Foundation initiated plans to establish the Enhancing Care Initiative (ECI) to improve the clinical care of people living with HIV/AIDS in resource-scarce settings. The key strength of ECI is the multisectoral and multidisciplinary AIDS Care Teams that lead analysis of HIV and AIDS care, design locally appropriate solutions in challenging contexts, and generate new evidence and best practices that are applicable in diverse settings. Through ECI, local care experts based in São Paulo and Santos, Brazil, in Dakar, Senegal, in KwaZulu-Natal, South Africa, in Northern Thailand, and in Western Puerto Rico work locally to address the status of AIDS care in specific communities and regions.

ECI is coordinated by the Harvard AIDS Institute in close collaboration with the François-Xavier Bagnoud Center for Health and Human Rights and the Department of Population and International Health at the Harvard School of Public Health. The initial grant from The Merck Company Foundation was supplemented by a grant from the United States Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB), which supports the ECI Puerto Rico AIDS Care Team.

This document presents the framework of ECI and the achievements of the individual AIDS Care Teams. A section on lessons learned provides insight into challenges and successes that were shared in all five ECI country settings, in the hope that these can be of use to others engaged in HIV/AIDS care in resource-scarce settings. The document concludes with a discussion of the future of AIDS care and treatment, and how the ECI model may be helpful in the new global context of expanded treatment and realistic awareness of the need for comprehensive clinical care integrated with prevention efforts.

When ECI was created five years ago, funding for and attention to programs that were attempting to improve AIDS care and treatment in resource-scarce settings were virtually non-existent. At that time, ECI represented a new way of conceptualizing AIDS care. That is, first, that HIV infection and its consequences can be treated in resource-scarce settings. Second, that local solutions to the difficulties of HIV care and treatment are best determined by local care experts. And, finally, that HIV care can and must occur throughout the course of one's infection—from the time of discovering that one is infected to the time of needing palliative care.

Today, AIDS care is well established as its own field, and approaches to care developed through multidisciplinary and multisectoral efforts are understood to be critical to an effective response to the needs of individuals living with HIV/AIDS. The five years of experience ECI can bring to current discussions of enhancing care in resource-scarce settings form the foundation of this document.
Building the Framework: Structure and Concepts

To achieve local, multidisciplinary, and multisectoral approaches to enhancing HIV/AIDS care, ECI facilitated the creation of AIDS Care Teams composed of, and directed by, local experts in HIV/AIDS care. The Teams brought together experienced clinicians, epidemiologists, human rights specialists, persons living with HIV/AIDS (PLWHA), leaders of advocacy groups, economists, religious leaders, government officials, academics, and public health specialists to focus on practical interventions that could be readily adopted within existing or expanding structures and institutions. The AIDS Care Teams were supported by faculty from The Harvard School of Public Health, by the International AIDS Care Resource Group, an expert advisory panel for the initiative, and most importantly, by local institutions and governments. Members of the International AIDS Care Resource Group were nominated by the AIDS Care Teams, and included leaders in HIV/AIDS care and policy making from UNAIDS, WHO, academic institutions, government and non-government organizations (NGOs).

A Local Focus for Care

For each AIDS Care Team, ECI activities began with an assessment using the ECI AIDS Care Framework. The framework focused assessment of HIV and AIDS care on existing infrastructure, local policies, programs, services and structures. This group undertaking resulted in adoption of a focus for team activities on which all Team members agreed. Initially, ten specific areas of care were identified through discussions with AIDS Care Team members in each of the five regions of ECI. The Ten Areas of Care shaped infrastructure assessments, and each Team focused their work in different areas according to needs determined through the results of the assessment. All of the ECI Ten Areas of Care are linked by cross-cutting “Care Analysis Themes,” which are topics common to many of the Areas of Care, including the epidemiology and availability of care, costs and economics, human rights, and involvement of individuals and communities, especially the integral role of HIV prevention interventions. In this way, regardless of

<table>
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<tr>
<th>Brazil</th>
<th>Puerto Rico</th>
<th>Senegal</th>
<th>South Africa</th>
<th>Thailand</th>
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</thead>
<tbody>
<tr>
<td>Total Population¹</td>
<td>182,032,604</td>
<td>3,885,877</td>
<td>10,580,307</td>
<td>42,768,678</td>
</tr>
<tr>
<td>Estimated number of adults and children living with HIV/AIDS (2001)²</td>
<td>610,000</td>
<td>23,546³</td>
<td>27,000</td>
<td>5,000,000</td>
</tr>
</tbody>
</table>

¹ CIA, Factbook. www.cia.gov/cia/publications/factbook
² UNAIDS, Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections. 2002 Update. www.unaids.org
which Areas of Care an AIDS Care Team selected as a priority for research, intervention, and the development of sustainable policy recommendations, their activities were linked by a common approach to assessment.

**ECI Ten Areas of Care**

Voluntary HIV testing and counseling
Basic medical care services
Laboratory and diagnostic services
HIV and AIDS clinical management
New therapies
Community-based care
Social services
Care education and information dissemination
Supportive care and care of the dying
Care of the caregiver

1. **Voluntary HIV Counseling and Testing (VCT)**

In the majority of cases, VCT is the initial entry point to care, and the method by which individuals learn their HIV status and are initiated into medical and social services. Ideally, identification of serostatus enables involvement in groups that provide support and education, which is key to improving quality of life and minimizing transmission. Stigma and fear, however, prevent many people from learning their status and accessing these services. To be most effective, counseling and testing must be supplemented with accessible treatment and sufficient care infrastructure. This supplementation, in turn, increases demand for VCT services.

2. **Basic Medical Care Services**

Insufficient access to medical care continues to be the norm in most resource-constrained countries. Primary health care and STD treatment and prevention\(^1\)\(^-\)\(^2\) can form the foundation on which more specialized AIDS service programs are sustained. In order to build this foundation, basic health infrastructure must continue to be a focus of AIDS care and treatment efforts. With sufficient infrastructure, basic medical care and complementary programs such as promotion of balanced nutrition or distribution of micronutrient supplements can be effective ingredients in AIDS care.\(^3\)\(^-\)\(^5\) As treatment becomes more accessible, the most effective care will ensure that medications are integrated into basic care according to primary knowledge of the specific needs of target populations.

3. **Laboratory and Diagnostic Services**

In the context of HIV and AIDS, effective care and treatment requires detailed clinical knowledge for which basic laboratory and diagnostic infrastructure are prerequisites. HIV testing, blood
screening, and hematology, CD4 tracking, and viral load are key components of comprehensive lab and diagnostic infrastructure. As opportunistic infections (OIs) become more common, the need for these basic capabilities increases in rural as well as urban settings. Although basic lab infrastructure is improving in many countries, gaps in coverage persist, especially in rural areas. Cost continues to limit training programs and efforts to scale up lab and diagnostic capacity. Continued research of low cost options for testing and diagnostics such as total lymphocyte counts is needed in order to make these services more widely available.

4. HIV/AIDS Clinical Management

In integrated clinical settings, trained personnel and clear care guidelines are integral to efficient management of scarce resources. Improvements in management can have a significant impact on care, even in the absence of antiretroviral treatment by streamlining clinic scheduling and maximizing the time that physicians can spend with each patient. When staff receive training in administration, management, and accounting, operational efficiency in clinics improves and staff are better able to support overburdened health care providers.

5. New Therapies, Including Antiretrovirals (ARVs)

In the five years since the launch of the Enhancing Care Initiative, several changes have occurred, including reductions in drug costs, which have increased the availability of ARV therapy in many resource-scarce settings. As more patients are treated, research and practice have revealed that comprehensive treatment pairs ARVs with infrastructure and education, specialized training, adherence and drug resistance monitoring, and continued research at all levels of health care.

6. Community-Based Care, Including Traditional and Complimentary Therapies

Since the start of the AIDS pandemic, community-based care has been a key resource in extending medical care to underserved areas. Patient care within the home (home-based care), traditional medicines, and peer adherence monitoring are all part of the medical and social programs that communities have developed to meet their own HIV care needs; it is estimated that traditional health therapies are used by between 60-80 percent of individuals living with HIV in resource-scarce settings. In many settings, however, coverage and quality of home care services are limited by lack of supplies, poor transportation, fatigued family members, and overburdened outreach workers. Long term success in care requires support for the key role that communities play not only in filling gaps in formal health services, but in providing overall care and support.

7. Social Services

When the most productive members of society fall sick and die, the financial impacts of AIDS can overwhelm traditional community resources. Social services that provide food, clothing, housing, transportation, or schooling for affected individuals and families create important safety nets. Varied service providers are necessary to adequately assess and utilize their individual resources and interests to address the economic and social consequences of the pandemic.
8. Care Education and Information Dissemination

One of the most persistent gaps in care is care education. While raising awareness and providing basic prevention education remain central to successfully addressing HIV/AIDS at the local level, training of medical personnel and community health workers for AIDS care has yet to receive sufficient attention. Ideally, efforts should be made to ensure that training is ongoing so that health workers have the most recent information regarding HIV/AIDS care.

9. Supportive Care and Care of the Dying

Several aspects of end of life care including amelioration of pain, communication with physicians, and emotional support are often under-prioritized. In many resource-scarce settings, even the most basic medicines for pain relief are lacking. Respect for the dignity and needs of dying individuals should be standard practice for all systems of care. Because AIDS-related deaths may occur at a time when a family's resources are depleted, social services may be needed to supplement care for the dying when available.

10. Care of the Caregiver

The HIV/AIDS pandemic has not only challenged the structures of communities and existing health services, it has also placed a significant emotional and psychological burden on health care providers and family members. Care of the caregiver addresses the fact that individuals infected with HIV are not the only people who are affected by the disease, and identifies areas in which caregivers are most in need of support. This can include attention to individual, group, and community support services, education, advocacy and referral services, and sources for the integration and dissemination of information on care of the caregiver.

Care Analysis Themes

Each of the ECI Ten Areas of Care were considered from the perspective of four common Care Analysis Themes.

Epidemiology and Needs of Target Populations

Analysis of the epidemiology of HIV provides information on the current status of the epidemic in a specific country or region, identifies the populations most affected, determines patterns of transmission, and projects future trends. Assessments of the care needs of people living with AIDS and care-seeking behavior requires that this information be part of the evaluation. In addition, identification of the needs of populations such as women and youth are highlighted.

Costs and Economics

The evaluation of the costs of the HIV/AIDS epidemic identifies expenses that affect the health care system, PLWHA and their families, particular sectors of the economy, and the nation as a whole. The economic assessment of costs associated with providing care and treatment is fundamental to the effective allocation of limited resources by government and other organizations.
Human Rights and Ethics

Examination of the state of human rights and HIV/AIDS care clarifies the legal and political context and the extent to which relevant laws, policies, programs, and practices protect the rights and dignity of PLWHA and their families. Of primary concern to ECI are questions of stigma, discrimination, and participation, as these relate to the utilization of services, and to quality of life. Ethical assessments should include an examination of value systems, identification of moral justifications for current policies, and evaluation of ethical codes of conduct in the design and implementation of research and the extent to which those codes are observed.

Involvement of People Living With HIV and AIDS

The Greater Involvement of People Living With or Affected by HIV or AIDS (GIPA) principles underscores the belief that effective and ethical national responses can only be achieved through the involvement of PLWHA at all levels, including planning, design, and implementation of prevention and care interventions.11

### Situation Analysis

<table>
<thead>
<tr>
<th>ANALYSIS</th>
<th>Epidemiology and Needs of Special Populations</th>
<th>Costs and Economics</th>
<th>Human Rights and Ethics</th>
<th>Involvement of PLWHA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary HIV Testing and Counseling</td>
<td>Example Issues: What is the cost of laboratory-related diagnostic services for HIV and AIDS in absolute terms and as a proportion of the overall expenditure for HIV and AIDS care?</td>
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<tr>
<td>Basic Medical Care Services</td>
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<tr>
<td>Laboratory and Diagnostic Services</td>
<td>What is the cost and effectiveness of laboratory training programs for improving the capacity to diagnose opportunistic infections or cancers associated with HIV and AIDS?</td>
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<tr>
<td>HIV and AIDS Clinical Management</td>
<td>Example Issues: Are policies, programs, and practices concerning informed consent and confidentiality in HIV testing in accord with human rights principles? What actions should be taken to ensure nondiscrimination in HIV testing practices?</td>
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<tr>
<td>New Therapies, Including Antiretrovirals</td>
<td>Example Issues: Are there clinical guidelines for HIV and AIDS treatment and chemoprophylaxis in use? What is the availability of drugs to treat or prevent the most common opportunistic infections and cancers associated with HIV and AIDS?</td>
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<tr>
<td>Community-Based Care</td>
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The Four Phases of Enhancing Care

Through the situation analysis based on the ECI framework, each AIDS Care Team determined two or more areas of care on which to focus. As priorities for care were identified, each Team worked through four phases of analysis and intervention, including the initial situation analysis, followed by research planning, implementation of interventions, and evaluation. After five years, comparison of differences in AIDS Care Team experiences in process and outcome within each of the four common phases can now provide a rich experience base from which lessons for enhancing HIV care in resource-constrained settings can be drawn.

Phase I: Situation Analysis

During the situation analysis, AIDS Care Team members collected available evidence regarding the status of each of the Ten Areas of HIV/AIDS care in their specific country or region, and analyzed the data according to the Team’s focus. The information obtained during this phase provided an overview of care, and identified gaps or deficiencies in care that might be addressed by ECI.

Phase II: Research and Planning

The situation analysis was followed by a planning phase during which the AIDS Care Teams selected an area of care to connect the needs of their country or region with the knowledge and resources available through the expertise of Team members. This phase used a “scenario planning” approach that considered various options for future policies, programs, and procedures directed at improving care, and assessed the feasibility of those strategies. Specific methods for improving care were determined during this phase. Proposed strategies for interventions were assessed on the basis of technical soundness and feasibility, accessibility, economic efficiency and sustainability, and ethical desirability and acceptability within their legal and political context.

Phase III: Implementation

Phase III involved the implementation of the interventions selected by each AIDS Care Team for improving the care of people with HIV/AIDS. Once the AIDS Care Teams identified gaps in HIV/AIDS care services, they considered strategies that could be implemented immediately given the current level of resources in their country or region. Due to constrained resources, strategies that required additional personnel, equipment, drugs, or facilities were usually foregone in favor of immediately feasible interventions.

Phase IV: Evaluation

Evaluation of the outcomes of interventions selected by each Team constituted Phase IV. Although the evaluation procedure itself represents a separate phase, the method for assessing the intervention began as part of the planning phase (Phase II) and was determined prior to the initiation of Phase III. Evaluation methods included standard process and outcome measures relating to the specific interventions led by each AIDS Care Team, as well as more generally applicable criteria that could be used across all Teams.
TEAM BRAZIL
SÃO PAULO & SANTOS

In Brazil, the concept of a multidisciplinary AIDS Care Team was defined by experts from diverse fields of knowledge who worked together to build a shared effort for enhancing care. The Brazilian Team includes experts in the fields of health programming, epidemiology, infectious diseases, pediatrics, psychology, and the social sciences, with collaborations in the areas of philosophy, epistemology, law sciences, and human rights. Several of the members of the Team are also professors at the University of São Paulo Schools of Medicine and Public Health. One Team member works at a public hospital, and another is a member of the São Paulo State STD/AIDS Program, and the AIDS Care Team’s psychologists are affiliated with the university’s Social Psychology department, the São Paulo State STD/AIDS Program and the Santos City STD/AIDS Program. Several members are also affiliated with AIDS service and advocacy NGOs. In this way, universities, state and municipal health programs, NGOs and PLWHA groups all play an important role in shaping the ECI comprehensive approach to health needs and disease management in Brazil.

Phase I:
Situation Analysis

The initial goal of the Brazilian AIDS Care Team’s activities was to develop responses from health services that addressed the specific needs of women living with HIV/AIDS. An epidemiological analysis conducted by the Team in 1998 showed that the São Paulo and Santos AIDS epidemics were growing faster among women than among men, and that mortality rates decreased more slowly among women, despite the universal availability of antiretrovirals in Brazil. In addition, mother-to-child transmission of HIV was higher than expected. Based on these results, practical experience, and empirical evidence of the central role that women play in managing illness and health care in Brazil, the Team targeted strategies to effectively reduce women’s morbidity and mortality. Quality of health care provided to women living with HIV/AIDS became the main focus of ECI Brazil.

The situation analysis indicated that São Paulo state had well-structured public health services and programs. The AIDS Care Team’s objective was to identify gaps and problems in the ongoing HIV and AIDS initiatives within these existing health systems. Team activities focused on the collection of empirical evidence regarding deficiencies in the care provided to women with HIV in order to help explain the small reductions in mortality and morbidity achieved within existing health programs among women as compared to men. Research objectives were developed in the context of the ECI Framework, integrating clinical care, epidemiology, and human rights perspectives.
The focus on services available to women was intended to identify both social and program-related vulnerabilities in HIV and AIDS care.

**Phase II and III: Research and Implementation**

**Enhanced Care for Women**

In order to assess the barriers to HIV/AIDS care for women living with HIV/AIDS in the region, the AIDS Care Team designed a cross-sectional study, combining a structured questionnaire with open qualitative questions. Between August 1999 and February 2000, 1068 women living with HIV/AIDS, including 116 recent mothers, were surveyed in seven different AIDS reference centers in São Paulo, Santos, and São José do Rio Preto. The questionnaires addressed a range of issues including socio-demographics, risk perception for HIV, knowledge and sexual practices, reproductive rights, adherence to treatment, and perceived quality of counseling and care.\(^{12}\)

The study found that women identified poor access to psychological support, dental, and nutritional care as major problems. In spite of high access to prenatal care, most women were not offered HIV testing while pregnant. Participants demonstrated a low perception of their own risk for contracting HIV, as well as a lack of understanding of HIV testing and counseling, and prevention of mother-to-child transmission. 47 percent did not receive appropriate contraceptive advice, a quarter of the women were not informed about the risk of HIV transmission during childbirth or breastfeeding, and less than 50% of the women had access to structured counseling.

Through this analysis, researchers identified several opportunities for improving voluntary access to HIV counseling and testing for women which existing health services had not yet exploited. The Team's analysis of the survey results also highlighted important failures in prevention of mother-to-child transmission of HIV in antenatal care and delivery assistance facilities and programs. Specialized infectious disease services required improvements in educating female patients regarding the benefits of follow-up tests, advice and access to contraceptive methods, and a better explanation of reproductive rights. The study findings and recommendations were presented to health professionals, activists, government officials and members of the media at an ECI-sponsored forum in São Paulo, and related papers were published in scientific journals.\(^{13, 14, 15}\)

The AIDS Care Team’s study of HIV/AIDS care for women was more than an academic exercise. Several health and social services used ECI findings to enhance their programs, including an improved health care service for women living with HIV/AIDS and their children in Santos. The clinic has moved towards providing for mothers’ and children’s needs within a continuum of care, and to deliver assistance to both in the same space and at similar times using a comprehensive approach.

The Team’s findings also helped enhance HIV/AIDS care for women in Santos by facilitating better integration of traditional women’s health services with HIV/AIDS care and encouraging special attention to reproductive health. The AIDS Care Team also worked to link these services to social support from government and NGOs, including food supplies, clothing, housing, and...
juridical support against discrimination at work, in the community, and in health services. In some cases, the government and NGOs were already addressing areas of ECI activities; in these situations the AIDS Care Team’s findings provided extra impetus for improvement, as in the case of initiatives to enhance voluntary HIV testing and counseling during antenatal care in the state of São Paulo. The Team has just finished an evaluation study on this service. The results suggest that integrated care programs enhance women’s adherence to care, and enhance the quality of assistance.

Securing a Future for Adolescents

In 2002, the AIDS Care Team’s work with women brought attention to the gaps in services, care, and support for HIV-positive adolescents. While antiretroviral therapy has been free and available in Brazil since 1996, a generation of Brazilian children who were born with HIV and provided with ARV therapy is now entering adolescence. The Team decided to focus its efforts on support for this population and their caretakers, including issues of sexuality, discrimination and disclosure. Consultations with policy makers and personnel from national STD/AIDS programs helped sharpen this approach.

With the objective of developing a comprehensive health care proposal, the Team designed a study protocol to identify and understand the psychosocial needs of adolescents living with HIV/AIDS. The qualitative study included interviews with adolescents who were already aware of their serostatus through AIDS services in São Paulo and Santos. Participants were selected from 248 potential candidates. Adolescents and their caregivers responded to questions regarding clinical and care needs, as well as questions about their schooling, work, social life, and sexual and reproductive health. Issues such as perceived vulnerability, awareness, effectiveness of counseling, social support, and human rights were also addressed.

In Brazil, the ECI AIDS Care Team recently completed rigorous qualitative research to determine the care and support needs of adolescents living with HIV/AIDS. Their data and recommendations are being used by state and municipal government officials to support campaigns for increased health services.

Nine Recommendations for Improving Health Services for Adolescents

- Increase adolescents’ and caregivers’ awareness of the rights of young people
- Increase local dialogue concerning stigmatization and discrimination
- Provide adolescents with current, clear, and accurate information
- Incorporate disclosure into the continuum of care
- Define the process of disclosure according to an individual’s context
- Include close friends and family in the disclosure process
- Emphasize team and caregiver support for disclosure decisions
- Increase health services targeted at the needs of adolescents
- Promote multisectoral collaboration to respond to adolescents’ needs for social and other forms of support
The Enhancing Care Initiative

Analysis of the qualitative research revealed several areas in which health services could improve their programs for adolescents, such as stigmatization and discrimination. Issues surrounding disclosure emerged as one of the main areas in which adolescents and their caregivers felt that improved services were needed. For many HIV-infected adolescents, fear of stigma or discrimination creates a barrier to seeking care or counseling, and inhibits their ability to interact freely with family and friends. Adolescents and their caregivers often expressed uncertainty and concern about how to disclose feelings that often lead them to avoid disclosure altogether. The resulting lack of social support and feelings of isolation made it difficult for many to live a ‘normal’ adolescent life following diagnosis. Often, the plans for future professions or relationships that occupy the imaginations of most teenagers seemed too improbable to consider.

Based on these findings, the Team has determined that increased attention to the challenges surrounding disclosure to and by adolescents must be a main component of improved health services in São Paulo. Disclosure, though a major turning point in the life of an adolescent, can often be handled poorly both by caregivers and healthcare providers. For example, doctors, counselors and families may postpone disclosing to adolescents their status in order to avoid difficult situations for which they fear the adolescents are not adequately prepared. Similarly, adolescents may postpone their own disclosure to friends, family, or significant others for fear of stigma or rejection. In order to avoid these situations, disclosure should be a process that is defined by multisectoral support structures that promote the acceptance and health of HIV-positive adolescents in all steps of the process. With attention to normal life progression, and proper handling, HIV-positive adolescents can be identified and cared for so that they believe they have a future worth planning for.

Impact of ECI in Brazil

The AIDS Care Team’s ongoing work has created new HIV/AIDS care services for women and adolescents. The state of São Paulo and the cities of São Paulo and Santos have expressed interest in the recommendations provided by ECI, and the AIDS Care Team’s leader was a member

AIDS in Brazil

1. In September 2003, 277,141 known cases of AIDS had been reported in Brazil since the beginning of the epidemic in 1980
2. General incidence is 15 AIDS patients per 100,000 inhabitants
3. Incidence among women is stable, with a slight trend to decline (11/100,000 women). The exception is women aged 13 to 19 years old, among whom incidence rates are increasing.
4. Twenty one percent of HIV positive males and 46.5 percent of positive females are aged 13 to 19
5. Sexual transmission is the most prevalent mode of infection, both between men (58% of the cases) and women (86.7%)
6. Though declining since the 90’s, the incidence rate in São Paulo state in 2002 was the 2nd highest in Brazil (20/100.00)

Source: Brazil Ministry of Health, December 2003
of a government task force on mother-to-child transmission prevention in 2002. The empirical evidence and recommendations developed by the ECI AIDS Care Team are currently being used by municipal government officials to support campaigns for increased health services in Brazil. In addition, Brazilian NGOs have used ECI’s data and comprehensive approach to obtain funding and support for advocacy and other initiatives. The results of the data analysis relating to women and adolescents could also benefit efforts in other countries, especially those that have established or are pursuing universal access to ARV therapy.

Plans for the Future

In the future, the international network established through ECI will strengthen the programs built on the Brazil AIDS Care Team’s work. The Team plans to develop a monitoring and evaluation tool to ensure that programs to improve care for women and adolescents will continue after the formal ECI project has ended. The ECI AIDS Care Team is currently seeking funding to extend their collaboration and approach to further focus on adolescents, AIDS orphans, stigma and discrimination.

The Team’s plans for the future also use the ECI structure to extend beyond Brazil. Initial arrangements have been put in place for a south-south cooperation between the South African and Brazilian ECI AIDS Care Teams. This collaboration will be designed to transfer Brazilian expertise on care planning and evaluation as the South Africa AIDS Care Team begins to implement and monitor its program on access to ARV treatment.
TEAM SENEGAL

In Senegal, the multisectoral concept of ECI was unfamiliar in that it differed greatly from familiar models of addressing social and health problems. ECI was first presented to Senegal’s National HIV and AIDS Committee leaders and National HIV/AIDS Control Program investigators in order to gain support at the highest levels of leadership. These leaders accepted the ECI framework as an effective tool, and welcomed the idea of collaboration despite the probable challenge of motivating potential members to take part in the initiative. The ECI Senegal AIDS Care Team has expanded to more than 40 experts, including private and public health officials, military physicians, biologists, pharmacists, nurses, midwives, social-workers, economists, lawyers, and representatives from PLWHA organizations. Team members continue to work with the National HIV/AIDS Control Program’s (NACP) in three committees on epidemiology, ethics, and economics, in relation to the ECI Ten Areas of Care.

Phase I:
Situation Analysis

As part of the situation analysis in Senegal, the specific care needs of populations in various areas were considered in the context of the three NACP committees. A national survey was conducted to evaluate the capacity and distribution of public HIV and AIDS health care services. The most important finding from the situation analysis data was the marked disparity in available HIV and AIDS care services between the capital city of Dakar and rural regions. Communities outside Dakar were found to have limited access to VCT and other related services; 60 percent of all health facilities offering HIV testing were concentrated in Dakar. In addition, the Team observed a need to train the health personnel engaged in HIV counseling, HIV testing, and laboratory diagnosis procedures.

Evidence of neglect and violation of human rights and ethical concerns related to PLWHA also caused concern within the Team. One issue raised within health care services was the fact that many health professionals neglected proper counseling before and after HIV tests, and sometimes did not inform patients of their test results. Many PLWHA and people seeking VCT experienced discrimination and stigma, and concerns remained over health facilities’ ability to keep test results confidential. The AIDS Care Team also observed a general lack of knowledge regarding virus transmission and safer sex practices among study respondents. As a result of the situation analysis, the Team identified several main priorities for improving HIV/AIDS care in Senegal. These included increasing access to VCT and treatment in rural areas, expanding programs to prevent mother-to-child transmission, addressing stigma and discrimination, establishing guidelines for care, building laboratory capacities, and training medical personnel to treat patients with HIV/AIDS.

Phase II and III:
Research and Implementation

Patient Consent and Opportunistic Infections

Interviews with physicians and members of the Senegalese Labor Physician’s Association revealed that protocols for patient rights and consent, along with guidelines for treating opportunistic infections (OIs) should be areas of focus. The AIDS Care Team visited 35 key health
facilities in three regions of the country to assess the prevalence of OIs, available diagnostic technologies, and access to medications for treatment. The study found inadequate capacity for diagnosis of most OIs at a majority of labs, and a lack of appropriate guidelines for OI treatment and management.

Based on these findings, the Senegalese AIDS Care Team recommended increased training of physicians in informed consent procedures and the creation of anonymous voluntary HIV testing centers. The Team developed and standardized guidelines for the management of OIs for use in health facilities. Educational posters were printed to illustrate and publicize the OI management guidelines, and additional posters regarding post-exposure prophylaxis were distributed to health facilities. Working with policy makers in Senegal, the AIDS Care Team recommended improved training of health personnel in the management of OIs and palliative care. This effort was supported by the government, which had already prioritized HIV/AIDS care training for physicians with the goal of swiftly improving medical infrastructure.

Urban/Rural Disparities in HIV and AIDS Care

One of the most important findings of the situation analysis was that gaps in medical infrastructure were restricting access to HIV/AIDS testing and care outside of Dakar, Senegal’s capital city. The focus on disparities in quality and extent of care between rural and urban populations was the result of the ECI approach, which stressed that research should be carried out by multi-sectoral teams of experts who are familiar with local realities. Following a survey of PLWHA and doctors treating HIV/AIDS patients in rural areas, the AIDS Care Team found that, in addition to lack of training, lack of confidentiality of HIV test results inhibited the effectiveness of VCT efforts. Continued attention to the urban/rural divide, and evaluation of the costs and cost-effectiveness of HAART emerged as priorities for research.

Cost Analysis of Opportunistic Infection Care in Senegal

Given the gaps in care observed, the AIDS Care Team decided to focus its research on assessment of the resources required for expanding HIV interventions outside of Dakar. A study of the costs of hospital treatment for common opportunistic infections including tuberculosis, derma-

Sharing the ECI Experience in Senegal

In December 2003, representatives of the five ECI AIDS Care Teams met in Dakar, Senegal for the 6th International Conference on Home and Community Care for PLWHA. In two sessions during the conference, the AIDS Care Teams presented the ECI framework and country-based strategies for building multisectoral teams for AIDS care in resource-scarce settings. The question and answer portions of the sessions revealed that the Teams’ experiences mirrored those in many other settings. Many of the attendees were from Senegal, which provided a unique opportunity to learn about the specific challenges of team building within the country. At the same time, the AIDS Care Teams were able to share best practices and offer ideas for problematic team contexts. One attendee from an NGO in Togo shared that he found the ECI sessions to be the most helpful of all the conference sessions he had attended.
The Enhancing Care Initiative

The study consisted of a retrospective review of the costs of treatment for HIV-infected patients who presented to both inpatient and outpatient settings in l’Hôpital Fann for OIs between 1998 and 2000. Costs of HIV-testing, counseling, inpatient care, drugs, and diagnostic tests were evaluated, and the financial impact on hospital budgets was assessed. This initial research convinced the Team of the need for more in-depth studies of the costs and cost-effectiveness of AIDS care and treatment in Senegal in the future.

Although challenging at times, the ECI model of collaboration benefited both the AIDS Care Team members and the HIV/AIDS situation within the country. The Team’s work to date has highlighted important deficiencies in the care provided to persons living with HIV and AIDS in Senegal. The AIDS Care Team also identified critical areas for improvement across a spectrum of disciplines that had been neglected in the past. In particular, minimization of urban and rural disparities in access to quality care was prioritized, and steps have been taken to address these disparities at national and local levels. The AIDS Care Team’s efforts also promoted a greater awareness of the need for training and capacity building regarding HIV testing and OI care in the country. The

Impact of ECI in Senegal

For many of the AIDS Care Team members in Senegal, ECI’s multisectoral approach to local problems was a new method of dealing with HIV/AIDS. As a result, many hours of planning and work were devoted to the process of convincing representatives of professional circles of the mutual benefits of working side by side with members of community groups. Over time, the AIDS Care Team found that defining concrete activities and establishing clear methods of communication were key to maintaining a common motivation to take part in the ECI. With each completed activity, Team members grew more motivated to work together for completion of the next goal.
AIDS Care Team continues to work closely with the NACP as it makes decisions regarding future interventions. This collaboration has linked Team members to policy makers, and has helped the NACP to set locally-appropriate goals for improving HIV and AIDS care in the country.

Plans for the Future

Analysis of the Costs and Cost-Effectiveness of Scaling Up HIV Care in Five Sites in Senegal

The Senegal AIDS Care Team’s future plans are focused on determining the most cost-effective interventions to scale up access to care in semi-urban and rural sites. Unfortunately, little data currently exists on the costs and cost-effectiveness of HIV and AIDS care in Senegal as a whole. As a result, the AIDS Care Team plans to undertake an economic analysis of HIV and AIDS care, and is currently developing a strategy for extensive evaluation of the costs and cost-effectiveness of expanding HIV interventions to sites outside of Dakar. The study will analyze the costs and cost-effectiveness of management of OIs, prevention of mother-to-child-transmission, improvement of post-exposure prophylaxis, and improvement of access to VCT in five regions. Computer-modeling simulations will be developed to project the costs and effectiveness of various interventions.

Preliminary data collection and compilation has already commenced regarding health system capacity and costs at specific sites in Senegal. Once analysed, this new data will fill an important gap in the cannon of research on HIV/AIDS in the country. Analysis of the AIDS Care Team’s data will help identify priorities for resource allocation and lend legitimacy to initiatives for increased availability of ARV therapy.

Overcoming Barriers to Team Building

In Senegal, the concept of a multisectoral team was new for many ECI members. Differences in styles of work and methods of communication created a challenge that the AIDS Care Team learned to overcome together. The following tools were most effective in the process of building Team Senegal:

- Defining specific plans for action and executing them
- Paying attention to members’ enthusiasm for specific team activities
- Taking time to discuss conflicts and concerns both individually and as a team
- Establishing clear, sustainable methods of communication
- Scheduling regular full-team meetings
- Dividing the team into smaller task-specific work-groups
- Mobilizing sufficient financial resources for sustained impact
TEAM SOUTH AFRICA
KWAZULU-NATAL

The resource-constrained province of KwaZulu-Natal (KZN) is home to the South African AIDS Care Team. Six sites were selected through the KZN health system, including tertiary, regional, district, and primary health care facilities. Since the site selection and group formation, the national HIV/AIDS policy has played a major role in shaping Team priorities in the region. The existence of an ECI AIDS Care Team was seen as a potentially important first step in improving specialized HIV/AIDS training for health care workers. Many health care providers also saw the AIDS Care Team as a vehicle to unite stakeholders to speak with “a voice of power” to national government health officials on the subject of making ARV therapy universally available, especially to pregnant women.

Seeking to create a group that is both multidisciplinary and multisectoral, the South African AIDS Care Team includes academic experts from the fields of epidemiology, health policy and planning, social and behavioral sciences, and health economics. Professors from the University of KZN’s Department of Medicine provide clinical skills for treatment protocols, medical care, and clinic- and hospital-based care, and specialists in the departments of pediatrics, obstetrics, and gynecology focus on the clinical aspects of maternal and child health care. Team members from the KZN Department of Health provide experience in policy formulation and supply contacts that facilitate program development among the district’s 70 hospitals and 240 clinics, which serve 8.4 million people. NGOs such as the National Association of People Living with AIDS (NAPWA) and faith-based organizations facilitate the full involvement and participation of PLWHA. The Team also includes representatives from the Durban Chamber of Commerce, and the Pietermaritzburg Chamber of Industries and Commerce. Collaborations with local and national government officials have been critical to the AIDS Care Team’s success.

Phase I: Situation Analysis

758 patients, 188 government health care providers, and 220 health care providers in the private sector from the six ECI sites (representing six of the nine health districts in the province) were interviewed for the situation analysis. The survey used qualitative and quantitative methods, and was conducted by trained field workers. Based on the results of the analysis, AIDS Care Team members chose to focus on the key issues for health care providers and HIV/AIDS patients. Challenges for health care providers were lack of funding to ensure access to care, lack of staff training, low morale, and a general lack of resources and capacity at all health institutions. Challenges for HIV-infected patients included stigma and the perceived threat of violence, which were major barriers to acceptable quality of life and to obtaining appropriate care and support. For many, learning their HIV-positive status resulted in societal or familial rejection, poverty, and, in some cases, severe illness, rather than facilitating opportunities to access care, counseling, and support services.

Given this information, the AIDS Care Team identified four priority areas for future projects: research and development, training and education, policy and planning, and community action. Initial projects focused on training and education, responding to the 96.3 percent of 220 health workers surveyed who indicated a need for specialized HIV/AIDS care training. The AIDS Care Team established the KwaZulu-Natal HIV/AIDS Training Program to provide health care work-
ers with accessible and immediately relevant training related to the unique issues faced by HIV/AIDS patients and their families. The Team has also worked in collaboration with the University of KwaZulu-Natal to establish the new HIV/AIDS Public Health Programme, piloted a VCT project using trained lay counselors, and conducted preliminary analyses of home-based care.

Care in a Changing AIDS-Policy Context

In KwaZulu-Natal, South Africa, AIDS Care Team members used multisectoral collaboration to develop and implement creative solutions to the challenges raised by inadequate medical infrastructure and severe poverty among the majority of HIV-infected people. The South African Cabinet’s recent announcement of a roll-out of HAART in the public sector of the health system has led to a shift in the Team’s work towards assisting the Department of Health with the HAART roll-out, and, in this changing context, providing a continuum of quality AIDS care.

The AIDS Care Team’s training program provides training on low-cost palliative HIV/AIDS care for health care facilities with limited access to financial and medical resources, and focuses on prescription and monitoring of antiretroviral therapies to prepare for administration of these drugs as they become more widely available. AIDS Care Team members have forged a unique partnership between regional government, the academic sector, and NGOs to prepare KwaZulu-Natal’s health care workers to distribute HAART effectively. In this way, the Team has learned and taught others in the region how to shore up limited medical infrastructure and to share experience and knowledge to strengthen all areas of HIV/AIDS care.

To address issues ranging from shrinking human resources at health care centers to poverty, the AIDS Care Team has partnered with local hospices and clinic counselors to consider better ways to care for PLWHA. The formation of support groups for PLWHA has helped to create a network of community support, and to reduce the pressure of stigma surrounding HIV infection. The Team’s partnership between the University of KwaZulu-Natal and the South Coast Hospice has also given the hospice’s palliative care and home-based care training programs an added level of academic and medical credibility.

Phase II and III: Research and Implementation

Building a Training Program

In collaboration with the University of KwaZulu-Natal, the AIDS Care Team originally planned to develop a training course in issues specific to HIV/AIDS management for key personnel at the six South African ECI sites. As the program was developed, the collaboration grew and now includes the Nelson R. Mandela School of Medicine and the university’s HIV/AIDS Public Health Programme, the Provincial AIDS Action Unit, the Provincial Department of Health, the National Department of Health, and the International Association of Physicians in AIDS Care. When
completed, the training program’s scope had expanded to a regional effort to train 30 percent of all KZN health workers in specialized HIV/AIDS care. The South African AIDS Care Team’s multisectoral approach encouraged participants from a wide variety of organizations and specialties to collaborate in producing a continuum of care well beyond the scale of what any one group could have supported on its own. The ECI Framework was used as a basis for the Training Program.

A series of Best Practice Seminars was developed as part of the Training Program to provide institutional management teams with an ongoing system for knowledge dissemination, and to introduce training on specific skills relevant to care and support of HIV/AIDS patients. The seminars also focused on informing healthcare managers and administrators of the specifics of the existing national HIV/AIDS policy guidelines. The Training Program includes a course for doctors and nurses to provide expert knowledge on the comprehensive clinical management of HIV/AIDS, and to prepare doctors for a new Post-graduate Diploma in Clinical HIV/AIDS Management Program at the University of KwaZulu-Natal. The course focuses on ways to improve quality of care and promotes an environment for ongoing knowledge dissemination. Through the mechanism of the Training Program, the AIDS Care Team plans to complete “gap analyses” of all health institutions in KZN.

Public Health and VCT

A second key project was the development of a program in the Department of Community Health at the Nelson R. Mandela School of Medicine to address HIV/AIDS issues. Using the unique approach mandated by ECI, the AIDS Care Team created an interdisciplinary academic program which provides students with knowledge and expertise in a wide variety of sectors to promote HIV/AIDS care.

One of the program’s areas of focus is voluntary HIV counseling and testing, a key entry point to care and support for both HIV-negative and -positive patients. In KwaZulu-Natal, the average time given to VCT per client was found to be eight minutes, while the recommended time for pre-test counseling alone is at least 25 minutes. In addition, the ELISA test used for HIV testing had an average turn-around time of ten days - a long period that resulted in poor return rates for follow up. There simply were not enough VCT health workers to properly meet the demand for their services. In an effort to improve this situation, a pilot group of ten Zulu women lay counselors were employed from 1999 to 2001. They had basic education, could speak both English and Zulu, and received intensive training on counseling, HIV/AIDS, sexually transmitted diseases, and tuberculosis. In this period, 8700 people were counseled, of which 50 percent were HIV positive, and 68 percent were women, with an average age of 28 years.

This study found that lay counselors were acceptable to, and considered essential by, health staff, and were perceived positively by clients. Rapid HIV tests were acceptable and preferable to the ELISA test. These results suggested that lay counselors and rapid HIV tests may be appropriate to other settings where prevalence is high, health services are lacking, and health personnel are overburdened from the impact of the HIV pandemic.

A Model for Home-Based Care

Through an assessment of the quality of care in home-, community-, and hospital-based settings in KZN, the AIDS Care Team created a model of home-based care from the perspective of caregivers and their clients. Quantitative and qualitative methods were employed to explore
various stakeholders’ ideas for feasible improvements to health care in resource-scare settings. Policy makers’ viewpoints were obtained through interviews of key individuals and complemented by analysis of official government documents.

Based on the study, the majority of patients supported the need for a continuum of care, with a strong emphasis on home-based care, and recognized that the policy framework was ambivalent, especially regarding treatment options. Programs at the community and health services level were found to be fragmented, unstructured, and highly dependent on the initiative of individual site coordinators. Service integration appeared limited, both within the health sector and among health, social, and education sectors. As such, the AIDS Care Team uncovered an urgent need for coherent, structured policy and programs for scaling up VCT, establishing HIV/AIDS care teams at health care institutions, and integrating home-based care into recognized health care frameworks.

Proposal to the Global Fund to Fight AIDS, TB and Malaria

On 7 August 2003, the South African Government approved the receipt of funds allocated to the Enhancing Care Initiative, KZN from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). The Nelson R. Mandela School of Medicine together with the Department of Health are key stakeholders in the implementation of GFATM funded programs in KZN. These programs were initially approved by the GFATM in April 2002.

The GFATM funding represents the largest HIV/AIDS implementation grant to South Africa to date, and is the Nelson R. Mandela School of Medicine’s first community-focused program of such a great magnitude. This unique horizontal program is intended to bring experts and stakeholders at the University, the Departments of Health, NGOs/CBOs and the private sector together to assist the Department of Health with a comprehensive HIV/AIDS implementation strategy, including provision of ARVs, which were not available when the GFATM grant was first submitted.

In line with Government’s ARV roll-out policy, and led by the Department of Health, the AIDS Care Team recently took part in collaboratively re-developing the proposal to complement the potential roll-out of ARVs in KZN. Overall, The ECI Team aims to bring together key stakeholders in HIV/AIDS programs in KZN with a vision to encourage best practices in response to local research, identified needs, and international standards of care.

Impact of ECI in KZN

By implementing the ECI Framework, the AIDS Care Team connected patients and caregivers to a new potential for quality care and collaboration. The Team’s AIDS care training courses continue to provide important educational opportunities for health care workers, with the potential to dramatically increase the number of trained specialists in the area of HIV/AIDS medicine in the underserved KZN province. These expert services are vital to the medical and mental health of patients, and allow both patients and caregivers to become part of a supportive and sensitive community. In the same way, collaboration fostered by the AIDS Care Team between the South Coast Hospice and the South African government has enabled clinics to form new hospice programs to provide PLWHA and their families with the option of care outside of a hospital setting.
At the strategic level, the AIDS Care Team has worked to integrate ECI’s Ten Areas of Care into the government’s district, provincial, and national AIDS Action Plans. Provincial-level goals include working with government officials to make health policy sensitive to and supportive of PLWHA, and providing adequate and cost-effective care. This initiative specifically includes the region’s 45,000 health professionals, with the goal of ensuring the availability of the resources and drugs necessary to implement government health policy in the public health sector’s 70 hospitals and 200 clinics. In addition, the AIDS Care South African Team used media coverage to highlight and combat the stigma that HIV/AIDS patients cited as a barrier to appropriate care and support.

Education and training have been a priority for this AIDS Care Team from its formation, leading to the development and present implementation of the short certificate course and the diploma-level interactive course for health professionals and NGOs throughout the province. A partnership with local government offices has sustained these programs, and has encouraged their utilization by medical workers and policy makers in KZN. In the future, this multifaceted approach will translate into a model of care that ideally will be relevant to other provinces within South Africa, as well as other resource-scarce countries.

**Plans for the Future**

**ECI KZN Plus**

Future models of care based on the work of ECI will focus on several areas. The AIDS Care Team’s vision of rapidly translating research into policy and practice has been extended by further funding in collaboration with Harvard University to form a research and implementation arm for the GFATM projects at the Doris Duke Medical Research Institute. This Team will be involved in operational research issues surrounding implementation of a province-wide HIV/AIDS training program. In addition, the Team will be a sentinel partner working with the GFATM
proposals consortium, and supporting the provincial Department of Health with the roll-out of HAART in the province. This additional effort, funded by the GFATM, is informally called ECN KZN Plus, and is based at the University of KwaZulu-Natal.

ECN KZN Plus currently has five main research tracks linked to the roll-out of HAART around which it will develop more projects in future: health economics; ethics and human rights; prevention of mother-to-child transmission; adherence and health systems and operational research. The Team is also leading several training programs currently under development at the University of KwaZulu-Natal such as a graduate Clinical HIV/AIDS Management Program, HAART training for nurses and clinicians and prevention of mother-to-child transmission training for the Department of Health in the province. The ECI costing model also led to a further grant from the Centers for Disease Control to assist KZN policy-makers by conducting research into the costs of improving prevention of mother-to-child transmission follow-up.

The Team specifically plans to focus on implementing a standardized program for the management of OIs, as well as a training program to prepare health care workers to prescribe and monitor ARV therapy. The Team will maintain a strong role as a mentor and advocate for new HIV/AIDS programs, specifically by creating and maintaining a “center of excellence” for training medical staff in the management of HIV/AIDS at the King Edward Hospital site. As a parallel effort, the AIDS Care Team plans to work with the South African government to develop infrastructure to deliver ARV, and to offer assistance in creating a new program.

In fulfilling its aims to develop research and training relevant to the HAART roll-out, ECN KZN Plus hopes to fulfill its commitment to working with partners in the province to provide optimal care to patients on HAART as well as to those who, for a variety of reasons, remain unable to access ARV therapy.
TEAM THAILAND
CHIANG MAI

In Thailand, ECI focused on identifying ways to improve the quality of life for PLWHA through partnerships with communities and programs for holistic care. The AIDS Care Team included six government and non-governmental agencies: the Faculty of Nursing at Chiang Mai University, the Office of Communicable Disease Control Region 10, the Chiang Mai Provincial Public Health Office, the AIDS Network Development Foundation, the Upper Northern People Living with HIV/AIDS Network, and the Church of Christ in Thailand - AIDS Ministry. A conceptual framework based on human rights norms formed the basis for designing initiatives. Past and current programs aim to enhance medical and nursing care, provide effective counseling, build community capacity for home-based care, strengthen referral systems and networking, and improve general levels of social acceptance and welfare.

Phase I: Situation Analysis

The Thai AIDS Care Team was fortunate to be able to draw on existing relevant data concerning the capacity and availability of HIV and AIDS services in northern Thailand, which had been gathered by Team members. For the situation analysis, the AIDS Care Team collected qualitative data through focus group discussions with HIV-infected individuals and their families, as well as with community health volunteers, community leaders, Buddhist monks, health personnel, and members of NGOs in the region. Data from interviews with health workers, care givers, and PLWHA revealed a perceived neglect of holistic care for terminal patients. Examination of care included end-of-life issues and pain management, physical management, mental and spiritual care, ethical aspects of care, and the legal and socioeconomic aspects of care. Based on analysis of this data, the AIDS Care Team targeted four areas for improving care in two districts of the Chiang Mai province: treatment, care, counseling, and social support.

Treatment and Care

In the northern region of Thailand, capacity for clinical care and treatment was limited by poor management of health services and lack of properly trained health workers. OI treatment and care guidelines were inconsistent and impractical, and the hospital referral system was not functioning effectively. In this context, home visits by health workers, though limited in coverage and effectiveness, became critical to care. Existing referral systems among health centers, hospitals, NGOs, community-based organizations, and groups or networks of PLWHA, however, were largely ineffective because of lack of collaboration between the agencies. When ECI began, the AIDS Care Team was the only multidisciplinary or multi-sectoral initiative related to HIV/AIDS care in the region. The process of coordinating diverse groups to improve existing structures was an early challenge for the Team because of the lack of services, as well as because of the lack of experience in working together.
Counseling and Social Support

At the beginning of the AIDS epidemic in Thailand, counseling was intended to be provided to PLWHA and their families by qualified professional counsellors. More than half of PLWHA surveyed by the AIDS Care Team, however, said they had received inadequate counseling for issues ranging from emotional support to coordination of end of life issues. In the context of home-based care, counseling is often provided by non-professional care workers such as religious leaders, traditional healers, community volunteers, or other HIV-infected persons. The AIDS Care Team’s analysis revealed a need to improve knowledge and skills for all kinds of health workers, especially the knowledge and skills for home-based counseling and counseling of the dying.

The situation analysis also indicated gaps in social acceptance and social support for PLWHA in certain communities. Most PLWHA surveyed reported that their needs were adequately respected and their dignity and rights adequately protected. Nearly all participants, however, agreed that knowledge and skills in protection against discrimination should be strengthened among caregivers and community members.18

Phase II and III: Research and Implementation

Two districts of Chiang Mai province were selected to be the target areas of study and intervention. Phrao district is a rural area located 100 kilometers away from the city of Chiang Mai, and Doi-Saket district is a suburban area located 30 kilometers from the city. In these areas, the AIDS Care Team focused on linkages between enhancing HIV/AIDS care through health institutions and the community sector. AIDS Care Team members recognized a correlation between economic stability, self-reliance, and community cohesiveness in rural northern Thailand. Poverty,
particularly in farming communities, and a lack of community support contributed to poor care and quality of life and stigmatization for PLWHA.

The AIDS Care Team worked to simultaneously improve clinic- and hospital-based medical care, and to teach affected communities the skills necessary to develop their own plans for self-sustaining projects. Team members worked with local leaders to create “empowerment” programs to teach methods of income generation and self care. This work was one of many ECI-built partnerships through which academic research was translated into concrete HIV/AIDS interventions.

**Enhanced Care in Institutional Settings**

One of the AIDS Care Teams’s interventions involved a collaboration with the Ministry of Health to standardize OI clinical treatment and care. The protocol was developed in 2000 through a series of workshops, and was designed for use at all levels of health care, including community hospitals. The Team also worked with the Ministry of Health to draft and implement guidelines and a training program for HIV/AIDS counseling in health care institutions. In addition, a study was designed to enhance the Universal Precautions Systems (UPS) used by health care providers in Chiang Mai. Medical staff participated in the development of these guidelines, resulting in a high degree of acceptance among medical workers, and quantifiable improvements in standard procedures. Guidelines for care of the dying were also developed based on study data, and health personnel were trained to provide counseling for dying patients based on these guidelines. The study found that the guidelines were a useful resource for care providers, and the AIDS Care Team recommended further research to improve the quality of end-of-life care.19

**People Research and Development**

The Thai AIDS Care Team’s first major initiative in the community sector was the People Research and Development (PR&D) project. PR&D was developed to enhance community capacity in problem solving and development, and was founded on the philosophy that community empowerment is the key to high quality of life. PR&D considers an individual’s potential capabilities rather than his or her problems. The AIDS Care Team was successful in implementing this process to enhance the role of community-based organizations with new knowledge and technology to manage their own resources. Through self-evaluation, community members verbalized new ways of thinking about sustainable community development. In this way, the PR&D approach has been successful in helping communities affected by HIV/AIDS gradually change their development paradigm from one of dependency on external sources to one of self-reliance.20

**Stigma and Discrimination**

To assess current levels of discrimination and stigma, AIDS Care Team activities were conducted with a particular attention to the cultural and legal aspects of HIV and AIDS related stigma and discrimination in Chiang Mai province. Data was collected through individual interviews and focus group discussions with PLWHA, affected families, and members of target communities. Health care personnel were approached separately, and programmatic, policy, and legal frameworks related to HIV/AIDS care in the region were also assessed. Based on the study’s findings, the first step was to increase knowledge of PLWHA in relation to national and regional
legislation. Guidelines for the protection of human rights in all AIDS Care Team activities were established and grounded in the cultural and ethical bases of Thai society.

Quality of Life

Improving quality of life of PLWHA was the ultimate goal of the AIDS Care Team in northern Thailand. Baseline data on quality of life including physical, mental, social, and spiritual well-being was collected from PLWHA in the 6 target sub-districts in Chiang Mai province, as well as from PLWHA in other regions who volunteered to participate in the study. The study results suggested that physical health, employment, acceptance, and support from family and community were perceived as critical elements of good quality of life. Based on this data, the AIDS Care Team developed an action plan that included community empowerment and improved social services. A future evaluation of quality of life will be performed to evaluate project effectiveness. The study indicated to the Team that in addition to addressing the symptoms of HIV-related disease, other living circumstances should also be prioritized to enhance quality of life.21

Impact of ECI in Thailand

Participation in the AIDS Care Team’s projects has helped communities to recognize and value local wisdom, culture, and relationships in addressing HIV/AIDS related issues. To this end, the Team conducted several training sessions focused on teaching skills that would enable individuals and communities to develop self-sustainable sources of income and food production. After the training sessions were completed, a group of PLWHA surveyed by the AIDS Care Team
The Enhancing Care Initiative reported greater self-confidence due to recognition of their knowledge and experiences by local leaders and health personnel. The group had obtained skills to provide more effective home-based care for their friends and families, and had also learned how to access care through the established referral system. Most PLWHA collaborators who worked with the AIDS Care Team reported that they had learned new ways of thinking, especially about HIV/AIDS, self-care and self-reliance, human rights, and the role of relationships in improving community health. With the support of health centers and hospitals, and with health personnel acting as facilitators, some PLWHA groups have begun to share their knowledge and skills with groups in other districts outside the ECI sites.

In response to the PLWHA enthusiasm for self-care, hospitals have tried to provide opportunities for PLWHA to participate in their own care, especially through the referral system and OI treatment policy. Hospital personnel reported that they wanted to learn more about the activities of the communities participating in ECI projects in order to form future collaborations between community groups and health care facilities. By working with the AIDS Care Team, health personnel have learned new ways of thinking about problem solving, community partnership, and community health as indicators of quality of life. They have also experienced and learned more about human rights aspects of HIV/AIDS work and care, which they have applied in their work. Encouragement and support for ECI collaborations and projects from the Provincial Public Health Office and the Office of Communicable Disease Control Region 10 were important contributors to this change.

Plans for the Future

The programs begun by the AIDS Care Team in Thailand are already serving as models for future HIV/AIDS care initiatives. In May of 2003, the AIDS Care Team presented their research and results to government stakeholders. Plans are already underway for a Center for Excellence in HIV/AIDS Care to be housed at Chiang Mai University's faculty of Nursing. In addition, proposals have been submitted to the government of Thailand and the GFATM for expansion of the community programs that the AIDS Care Team helped establish in provinces that lacked AIDS programs.

Internationally, the Thai AIDS Care Team has worked with a multidisciplinary team from Sichuan and Yunan provinces in China to help them to develop the “China HIV/AIDS Prevention and Care Project.” The Team is now working with Chinese collaborators to plan a model of care based on the ECI Framework to be implemented in China. The South East Asia division of WHO Nursing programs has also contacted the AIDS Care Team to design a training course for nurses in 2004. Several international training programs on HIV/AIDS prevention and care have already been carried out by the Faculty of Nursing, Chiang Mai University. To date, 233 participants from 17 countries have been trained. Lessons learned from the ECI experience have been shared with representatives from several countries where care programs are just beginning, including Afghanistan and East Timor. Despite this international attention, however, strong community relationships continue to be the hallmark of ECI Thailand. AIDS Care Team members remain in regular contact with their rural partners, and are often asked to participate in decision-making and special events.
TEAM PUERTO RICO
WESTERN REGION

ECI serves the western region of Puerto Rico which includes the fifteen municipalities of Aguadilla, Aguada, Isabela, Moca, San Sebastián, Lajas, Sabana Grande, San Germán, Añasco, Cabo Rojo, Hormigueros, Las Marias, Maricao, Mayagüez, and Rincón. The main office is located at Estancia Corazón, Inc, in Mayagüez, Puerto Rico.

The purpose of ECI Puerto Rico is to support the assessment of HIV/AIDS care in the western region of the island by developing a systematic approach and a structural mechanism to facilitate and promote collaboration between multiple service organizations. This collaboration is designed to result in concrete improvements in the care of PLWHA, their families, and caregivers. Partner organizations include health care, drug, and mental treatment centers, central, local, and municipal governments, residential treatment facilities, soup kitchens, emergency shelters, academic institutions, NGOs, and PLWHA associations. Overall, ECI Puerto Rico’s multisectoral partnership includes a team of 27 members. This AIDS Care Team has succeeded in bringing together a multisectoral collaboration combining their academic, research, municipal, personal, and agency resources to identify and meet the needs of the local situation.

Comprised of over 300,000 residents, the western region of Puerto Rico with its mountainous topography and shortage of mass transportation lacks many health services. Health service providers possess limited capability, and health care agencies rarely work together to provide services. According to the Puerto Rico Labor Department, 22 percent of people living in the region are unemployed, 85 percent are below the federal poverty level, 85 percent are Medicaid (a US government funded medical program) eligible, and 80 percent of the population is considered medically indigent. The region’s high rates of teen pregnancy and births are comparable to other Latin American countries immersed in extreme poverty, such as Brazil and Haiti.

Phase I and II: Situation Analysis and Research

Prior to ECI, there was no research on the needs of PLWHA or the services available to them in the western region of Puerto Rico. The Puerto Rico AIDS Care Team conducted a needs assessment and situation analysis by gathering information from physicians, caregivers, and PLWHA from six agencies that provide HIV/AIDS services in the western region. Data collection included qualitative interviews, focus group discussions, and the administration of a Social Support Questionnaire and an AIDS Knowledge Questionnaire, adapted from a questionnaire designed by the students of the Medical Sciences School of the University of Puerto Rico. The questionnaires examined attitudes toward availability and quality of health care facilities and health workers. Issues of personal health status were also examined, including perceived benefit from services received and the negative effects of illness, such as depression, loss of income, and social isolation. Responses were evaluated based on the Center for Epidemiological Studies Depression Scale, Life Styles and Sexual Practices Scale, Evaluation of Services Scale, Needs Checklist, and AIDS-Related Symptoms Checklist in order to identify a PLWHA profile and assess the comprehensiveness and accessibility of HIV/AIDS services in the region.

The AIDS Care Team’s survey revealed that symptoms of depression are present in 98.1 percent of PLWHA in the region. Data analysis revealed that depression is significantly correlated
Managed Care in the Western Region of Puerto Rico

According to the 1993 Puerto Rico Health Act, the island’s government-owned traditional health care system was replaced by private insurance carriers that contract with provider organizations for managed care services. In June 1998, the western region was the last region integrated into the new policy of managed care. Managed care, a “holistic system of clinical and financial organizations partnering to provide health care in a cost efficient way”, was expected to achieve better health outcomes by anticipating patient needs and quickly linking patients with appropriate services. In the western region however, the effectiveness of managed care in addressing and providing physical and mental health care for vulnerable populations such as drug users, who are at high risk for HIV infection, is uncertain. Under the former system of health care, indigent and uninsured individuals were able to access services with little or no cost. The region’s relatively short history with managed care, however, has not yet revealed whether these highly vulnerable groups will be able to receive sufficient care under the new system.

Phase III and IV: Implementation and Evaluation

All AIDS Care team activities are guided by a set of core principles that were collectively developed and agreed upon by Team members. First, open communication regarding project guidelines, objectives, activities, and roles and responsibilities is and will continue to be the foundation of all ECI work. Second, continued identification and coordination of members’ strengths, resources or connections, priorities, and interests will enable the AIDS Care Team to best utilize its resources despite changes in membership. Commitment is the third element of the Team’s core principles, such that member involvement will be based on their individual strengths, resources, and interests. Finally, collaboration in resolving difficulties and developing

Regional Demographics
(Surveillance Report January 2004)

AIDS cases in Puerto Rico: 28,227
AIDS cases in Western Region: 2,285
Adult/adolescent cases: 98.9%; Pediatric: 1.1%
Estimated Ten HIV cases per identified AIDS case
workplans, research design and data collection tools will continue to be part of regular Team meetings. In anticipation of successful implementation, the AIDS Care Team has developed a protocol for self-monitoring and evaluation based on these core principles.

Impact of ECI in the Western Region of Puerto Rico

Even prior to the actual implementation of interventions, the AIDS Care Team’s collaboration has had significant impact on the western region. Several Team members are also part of CBOs in the region. These individuals drew on the relationships they built as ECI partners to encourage collaboration among CBOs that once competed against each other. For example, based on the ECI model of multisectoral partnership, the Coalition for the Homeless in the Western Region has been reactivated and was incorporated in December of 2003. A Center for Studies for Professionals has also been established for continuing education for health professionals working with HIV/AIDS.

ECI’s example of multisectoral collaboration is not the only aspect of the initiative that has gained attention and achieved results. Central and local government organizations have contacted the AIDS Care team to request the results of the situation analysis for use in grant applications. In response to the Team’s assessment of underserved areas, the region’s Migrant Health Clinic expanded its mobile unit that complements existing medical services by helping to identify and serve HIV positive persons in hard-to-reach areas.

Principal Transmission Modes:
- injecting drug use (45.5% males, 35.6% females)
- heterosexual contact (19% males, 64% females)
- men who have sex with men (25.3%)

PLWHA Needs:
- economic support (70.8%)
- short and long-term housing (50%)
- psychological services (40.1%)
- medication (34%)
- medical treatment (37.7%)

Preliminary results of the Puerto Rico Team’s situation analysis have not yet been analyzed. These new insights into transmission and PLWHA needs, once analyzed, will help the team develop interventions that are relevant to local contexts.
Plans for the Future

A primary goal of the Puerto Rico AIDS Care Team is to continue to foster coordination of care through inter-agency collaboration. Two specific events that will support this goal are the design and implementation of a Caregivers Workshop for health care providers in the western region and the participation of the AIDS Care Team in the Puerto Rican Homeless Summit. In addition, preliminary meetings have been held with senior administration at local universities regarding the initiation of an inter-university collaboration to form an AIDS research institute. The goal of all these activities would be to foster an environment in which individuals and organizations join their experience, influence, and resources to improve HIV/AIDS care in western Puerto Rico.

Benefits of Membership in ECI Puerto Rico

In October 2003, the AIDS Care team met for a three-day monitoring and evaluation workshop. Along with developing a strategy for evaluating future interventions and research, the Team participated in a focus group discussion of the non-monetary benefits of being part of the ECI. The following benefits were identified:

- Student involvement in meaningful research benefiting the western region of Puerto Rico
- Professional relationship building with professionals with similar interests
- Personal and professional growth opportunities
- Materials and resource availability
- Translating research into practice that makes a positive impact in the community
- Feelings of hopelessness are transformed into hope by being part of a group filled with energy, resources, and commitment
The AIDS Care Teams worked in different regions of the world, dealt with different political contexts, and functioned with different combinations of challenges and resources. Despite all these differences, several common lessons emerged. Over the five years of the ECI experience, representatives from each of the AIDS Care Teams have had the opportunity to come together at conferences and events to share best practices, discuss concerns, and determine next steps. In the beginning, the AIDS Care Teams were surprised to learn that they shared many of the same insights into the steps necessary for team building and enhancing care. Over time, however, the Teams have come to recognize each other as partners in a common mission with shared experiences despite distance and difference. As a result, we believe the following lessons are relevant not only to the ECI AIDS Care Teams, but to many multisectoral efforts to enhance AIDS care in resource-constrained settings.

1. **Build Flexible Teams**

Coalition building and partnership development are foundational aspects of the Enhancing Care Initiative. In all five ECI countries, health care institutions, PLWHA, universities, NGOs, and government officials began to work together to design and implement HIV/AIDS care intervention, research and programs within a continuum of care. Although the process of building this kind of joint effort has not been easy, the partnerships created through ECI are enabling unique approaches to impact AIDS care.

Working together to forge a common agenda often led to reevaluation of priorities, and required that inter-disciplinary conflicts and inherent institutional competition be overcome in the interest of attaining a larger goal. The AIDS Care Teams found that a willingness to reevaluate roles and responsibilities over time was critical to this process, as different individuals or groups were most appropriate to lead during different stages of project development. Shifts in leadership also helped to sustain the long-term engagement of partner institutions. Team composition also shifted over time, as new priorities required the involvement of new participants. In Brazil, for example, composition changed when the care of adolescents with HIV and AIDS emerged as a priority, necessitating the greater involvement of specialists in adolescent care. Similarly, the Senegalese AIDS Care Team is currently recruiting additional economists to better support the upcoming analysis of the costs and cost-effectiveness of HIV/AIDS treatment.

2. **Focus Locally, Impact Nationally, Think Globally**

Recruiting and sustaining the engagement of local experts familiar with the different aspects of HIV/AIDS is essential to ECI. The full involvement of diverse local capabilities and resources has lead to new and unexpected programs and problem-solving techniques. For example, the Thai AIDS Care Team uncovered the importance of strong personal commitment from community members and leaders, and developed its unique People, Research, and Development approach.
to AIDS care. In rural Chiang Mai, as in KwaZulu-Natal, communities have mobilized with little outside assistance to create volunteer hospice care, food, and childcare. Traditional healers and religious leaders are working side by side with teachers and nurses to care for themselves and their communities as part of these initiatives.

In the diverse settings of ECI, the term local is defined according to country realities, and may refer to certain cities, a region, or a whole country. For example, in a large country such as Brazil, the AIDS Care Team is made up of experts based in, and initially prepared to focus their efforts on, São Paulo and Santos. The Brazilian Team’s research and recommendations, however, are being translated into policy recommendations that are relevant to HIV/AIDS care needs in the rest of the country. In the same way, universal precautions and best practices developed by the Thai Team for health care providers in Chiang Mai province are beginning to be adopted nationwide. The Puerto Rico and South Africa AIDS Care teams are located in areas where HIV prevalence rates are much higher than rates in other regions within these countries. These AIDS Care Teams have worked with organized advocates to ensure that their traditionally underserved regions are included in national HIV/AIDS policy, as well as in programs designed to better utilize scarce resources in highly affected localities.

Just as ECI lessons learned at the local level have impacted policies at the national level, these lessons are also crossing national borders to enhance care around the globe. In addition to partnering with other countries to develop programs as in the case of Thailand and China, the ECI AIDS Care Teams have published numerous abstracts and academic papers. Representatives from the Teams also present regularly at major international conferences including the International Conference on Health Resource Allocation for HIV/AIDS and Other Life-Threatening Illnesses, annual Harvard International AIDS conferences, the International Conference on AIDS and STDs in Africa, the International Conference on Home and Community Care for Persons Living with HIV/AIDS and the XIII, XIV and upcoming XV International AIDS conferences.

3. Foster Knowledge and Team Communication

Diversity of membership within each of the AIDS Care Teams has been one of ECI’s greatest resources. This diversity, however, has also made communication within the Teams challenging. Language barriers (even across sectors), disparities in education levels, and cultural differences have all created obstacles to working together effectively. Simple approaches like regular meetings and internal evaluations have been the most effective in improving group dynamics. In some cases, an “executive committee” was formed from among the Team’s members to facilitate decision-making, conflict resolution, and project administration. By actively fostering internal communications, the Teams have been better able to collaborate with external partners, including other AIDS Care Teams.

Communication among the five AIDS Care Teams has brought ECI’s local perspective to a global audience. Since the beginning of the ECI, Team leaders and members have gathered together in conjunction with international HIV/AIDS conferences once every six to nine months. These meetings created a forum to share approaches, results, and concerns. Throughout the course of ECI, important changes to the AIDS Care Framework, methods of evaluation, and plans for the future of the initiative have been developed through these joint team discussions. In this way, the meetings not only improved the structure of ECI, they also exposed the Teams to a global support system. Relationships with experts from around the world added value to local efforts, and provided a means for the AIDS Care Teams to share best practices with other AIDS care practitioners.
4. Research and Implement According to Needs

Through ECI, researchers, policy makers, and practitioners from different fields meet at a common table. The process of partnering to complete and implement the situation analysis mobilizes the range of partners represented to directly impact programs and policy. In this way, research leads to action. The need for improvements to care was so urgent in some areas, however, that interventions were initiated before the formal process of results dissemination was complete. As a result, some AIDS Care Team programs were well established before publication of research results.

Although this flexibility in the order of the four phases of ECI was not anticipated at the outset, the change was in accordance with the overall ECI belief in locally-motivated action. Contrary to initial concerns, implementation did not take the place of research, and in some cases actually made the Teams more prolific. By allowing research agendas to be shaped by needs, AIDS Care Team findings were enriched.

5. Indicators of Success Take Time

Quantifiable results such as established programs or published papers are the result of hard work by individuals and AIDS Care Teams. Strong personal commitment, compromise, and collaboration are all required in order to establish and maintain the symbiotic working relationship necessary for an effective ECI AIDS Care Team. In each Team, it took time for individual members to feel comfortable enough to put aside their priorities or institutional agendas in the interests of identifying and achieving group monitoring and evaluation frameworks. Partnerships within and among AIDS Care Teams were strengthened by individual dedication to making ECI a success.

In the same way, AIDS Care Teams developed and agreed upon short and long term indicators through a long process of research, discussion, compromise, and innovation. Program evaluation thus required as much effort as program development and implementation. Efforts were structured to ensure that indicators were both locally appropriate and globally relevant. The careful, and sometimes lengthy, work to define these measures as well as to measure success should not be underestimated.
Conclusion: The Future of Enhancing Care

When the Enhancing Care Initiative reaches the end of 2004, many of the programs initiated by the AIDS Care Teams in Brazil, Senegal, South Africa, Thailand, and Puerto Rico will continue. The Teams have worked to secure future internal support and external funding for their programs. In many ways, the ECI multisectoral Framework has prepared the AIDS Care Teams for this difficult task. The Global Fund, for example, requires applicants to form multisectoral “Country Coordinating Mechanisms” (CCM) in order to receive funding. ECI countries are already able to demonstrate the value of these mechanisms, as well as the efforts required for them to be successful. For example, the experience of ECI was an asset to the South Africa AIDS Care Team, which had coalitions in place when the Global Fund issued a call for proposals, and is now taking a key role in determining how best to disburse GFATM funds.

As this document has described, the ECI AIDS Care Teams have been able to develop programs that are immediately useful to communities and require minimal additional resources to operate effectively. Through the personal and professional commitment of individual AIDS Care Team members, the benefits of a multisectoral, local approach to improving HIV and AIDS care are evident today in the five ECI countries. The Teams believe that sharing these benefits will add to the value already created by ECI. To this end, a training guide for team building is being developed, and will be available for the first time at the XV International AIDS Conference in Bangkok. Future publications in academic journals will also be part of sharing the ECI experience with a broader audience.

The success of the ECI AIDS Care Teams demonstrates local capacity to mobilize resources and influence policy agendas according to community needs. In addition, the work of the AIDS Care Teams shows that dedicated involvement of local care experts can enhance care even in settings where resources are scarce. The ECI Framework will continue to be an important tool for the AIDS Care Teams as they pursue new initiatives and expand their networks to include new partners. For future multisectoral AIDS care partnerships, the ECI Framework, the experience of the first five teams, and the lessons they learned will be evidence that a multisectoral initiative can effectively enhance HIV/AIDS care in the places where care is needed most.
Acknowledgements

Contributors

Harvard facilitators Sofia Gruskin and Richard Marlink guided the creation of this publication. Input from the AIDS Care Teams ensured that the information presented is not only current, but representative of local realities. José Ricardo Ayres, Mandisa Mbali, Karen Michael, Pikul Nantachaipan, Ibrahima Ndiaye, Robert Pawinski, Daniel Pimentel, Prasit Saetang, Wilawan Senaratana, and Gloria Asencio-Toro offered invaluable insight and feedback. At Harvard, Marcio Maeda managed administrative details, Partricia J Burns oversaw the Puerto Rico team sections, and Paula Telch brought the words to life with powerful images. Katherine Holland skillfully compiled the content and wrote the text.

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19. Srithanaviboonchai K. “Enhancing care for the dying as part of comprehensive HIV and AIDS care: experiences from upper northern Thailand.” In: V International Conference on Home and Community Care for Persons Living with HIV/AIDs; 17-20 December, 2001; Chiang Mai, Thailand.


### AIDS Care Team Directory

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<th>Name</th>
<th>Title/Position</th>
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<td>Physican</td>
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<td>Omar Sylla</td>
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<td>Neide Gravato</td>
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<td>Mournirou Ciss</td>
<td>Pharmacist</td>
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<tr>
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<td>Moustapha Sow</td>
<td>Physician</td>
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<td>Nathalie Ndiakhat</td>
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<tr>
<td>Abdoulaye S. Wade</td>
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<tr>
<td>Ismaela Goudiabty</td>
<td>Nurse</td>
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<td>Louis Martin Diouf</td>
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<tr>
<td>Ismaila Mbaye</td>
<td>Physican</td>
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<tr>
<td>Saiba Sissoko</td>
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<td>Aissatou G. Diallo</td>
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<td>Papa Fall Sow</td>
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<tr>
<td>Papou Moussa Ndyoe Aissatou G. Diallo</td>
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<td>Mame Awa Touré</td>
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