AIDSTAR-One | CASE STUDY SERIES July 2012

Integrating HIV Care: Improving Programs, Improving the Lives of People Living with HIV


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Staff and volunteers, Village Information Center, Kolhapur.

It is a blisteringly hot day in the city of Sangli in Maharashtra, a southern state in India. A group of women and men living with HIV have come together at the Aamhich Aamache Drop-In Center (DIC) to talk. Several women tell harrowing stories of the stigma and discrimination they received at the hands of their family and community. Speaking in a whisper, a man talks of his wife who, after months of such stigma, took her own life, leaving him behind to raise their children.

As time passes, though, the stories move from despair to triumph. Many of the women are involved in income-generating activities which, for the first time in their lives, provide them with economic stability and freedom. Men and women alike describe how addressing their own internalized stigma has allowed them to advocate for themselves with clinic staff, service agencies, and communities, demanding that their rights be honored and they be treated and cared for with dignity and respect. They are able to better navigate a complex system of clinical and social support services, with the assistance of counselors and peer advocates.

The services provided at the DICs are a central part of the Integrated Care Program (ICP) implemented in selected districts in Maharashtra. Launched in 2010 in six high-prevalence districts in Maharashtra, the ICP quickly resulted in significant improvements in service utilization by people living with HIV (PLHIV) while enhancing the quality and continuity of comprehensive care and diminishing the loss to follow-up (LTFU). The ICP builds individuals and institutions through its main strategies of working with existing public, private, and community

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This publication was made possible through the support of the U.S. Agency for International Development under contract number GHH-I-00-07-00059-00, AIDS Support and Technical Assistance Resources (AIDSTAR-One) Project, Sector I, Task Order 1, funded January 31, 2008, and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).

institutions and resources; linking PLHIV with the full range of HIV care and services; and providing PLHIV with the tools to improve their own lives. The staff of the DICs, many of whom are PLHIV themselves, perform critical functions as coordinators of the network of services.

For the clients who use the DICs, the centers are a haven. As one women said, "When I come to the drop-in center, I feel like I've come to my mother's home."

Background

India has made significant progress addressing the HIV epidemic. As a result of comprehensive planning and government and donor support, the country began to witness a decline in HIV prevalence in 2000; prevalence dropped from 0.41 percent to 0.31 percent in 2009. While this is good news, much needs to be done to scale up testing and care and treatment services. The National AIDS Control Organization (NACO) sets national strategies for HIV management with decentralized implementation by state- and district-level agencies. NACO set a goal of diagnosing 80 percent of PLHIV and providing them with quality care and treatment services by 2015. Of the nearly 2.39 million adults and children living with HIV in India, over 1.2 million are registered with the government. NACO is also scaling up antiretroviral treatment (ART) services. Currently, there are 486,173 people who receive ART through a network of 342 government-run ART Centers and 579 ART Link Centers (outside major urban areas). Unmet needs remain high, however; more women than men receive ART, and relatively few children benefit from this lifesaving therapy (NACO 2011).

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With success, come challenges. With increased access to ART for the management and treatment of HIV, the issue of adherence—recognized by the World Health Organization (WHO) as fundamental to the treatment of chronic disease (WHO 2003)—has become even more prominent. Increased numbers of people in care and on treatment burdens an already stressed health and social support system. Clinics are crowded and staff are taxed by the volume of clients and the increasing complexity of their clinical and social support needs. Programs struggle to attend to the increasing number of new clients and people who have been in care, with little or no time to focus on the challenges to care and adherence, such as the enrollment of PLHIV in DICs, referral for other health services, decentralization of care, missed visits, and especially, LTFU. Adherence has been identified as a significant challenge and public health issue for both patients on ART and those not yet clinically eligible (Amuron et al. 2009; Berg et al. 2005; Cauldbeck et al. 2009).

These challenges are especially urgent in Maharashtra, one of India's high-prevalence states. Adult prevalence in Maharashtra is higher than the national rate (0.55 percent); 443,620 children and adults live with HIV. More than half (261,442) are registered, and 90,484 adults and 6,301 children are on ART, receiving care from 51 government ART Centers and 85 ART Link Centers. HIV is concentrated in high-risk groups such as female sex workers, men who have sex with men, and migrants (NACO 2011).

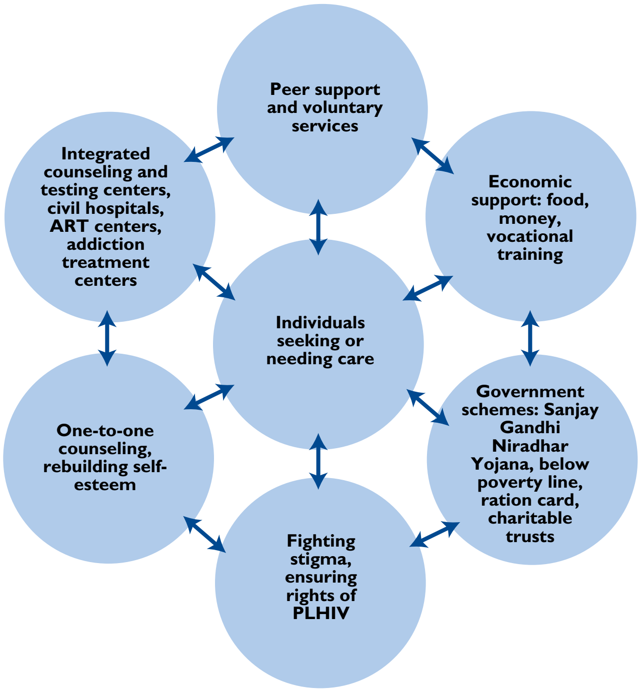
Until recently, the relationship between clinical programs and community-based efforts in Maharashtra was weak and strained, characterized by underperforming linkage and referral systems, duplicative efforts, and ineffective communication.

In response to this situation, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development (USAID), worked with NACO, the Maharashtra State AIDS Control Society (MSACS), and the Avert Society,[1] a local nongovernmental organization (NGO) to develop and implement a comprehensive, integrated HIV care program—the ICP—in six high-prevalence districts of Maharashtra. The ICP, launched in 2010, brought together a broad range of government stakeholders, community-based service providers, and NGOs to design, implement, monitor, and evaluate medical and social support services for families and individuals living with and affected by HIV that would improve enrollment and decrease LTFU and serve as a model for consideration by other districts in the state and, more broadly, in India. This document describes the development, components, and accomplishments of the ICP. Information was gathered through a review of Avert Society and DIC documents and field visits to five of the six ICP districts, and through interviews and focus groups discussions with district government officials, medical providers, and DIC staff and clients.

Designing and Implementing the Integrated Care Program

When the planning for the ICP began, many of the necessary components for comprehensive HIV services were in place, including government structures and coordinating bodies, HIV treatment centers, and NGOs dedicated to meeting the needs of PLHIV and high-risk groups. The Avert Society, which functioned as the lead coordinating body for the ICP, built upon the existing infrastructure and programs in the districts, identified opportunities to strengthen what was available, and improved links among service delivery partners. Figure 1 details the services and relationships that comprise the ICP approach implemented in Maharashtra. As the figure shows, no single provider is capable of providing the entire scope of services needed by PLHIV and their families. PLHIV require a complex set of services that are accessed through referrals within and among health facilities, other welfare and support programs, and the community. Hence, the ICP's principal components include stakeholder coordination, service linkages for clients through the DICs, and support for decentralized services.

Figure 1. Elements of the Integrated Care Program in Maharashtra



Source: recreated from Avert Society (2010).

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[1] The Avert Society is a Maharashtra-based NGO created through a bilateral agreement between the governments of India and the United States. Avert collaborates with MSACS to support HIV management strategies by providing technical assistance to a variety of programs, including the ICP. This NGO's focus is on reaching high-risk groups. The intention at the inception of the ICP was for the leadership of the ICP to be transferred from the Avert Society to the District AIDS Prevention and Control Units once the program was established.

SERVICES PROVIDED BY DROP-IN CENTERS

1. Psychosocial support and counseling
    - Individual counseling
    - Self-help groups
    - Stigma and discrimination
    - Disclosure
    - Prevention with positives
    - Condom distribution
    - Nutrition
    - Adherence support
    - Child support
    - Couples counseling
2. Peer support
    - Stigma and discrimination
    - Disclosure
    - Adherence support
3. Referrals
    - Government schemes
    - Child and widow services
    - Medical care and support
    - Missed visit follow-up
4. Advocacy
    - Legal services
    - Property
    - Improved health and social services/pressure groups
5. Economic opportunities
    - Income generation activities
    - Skills training
    - Employment opportunities
6. Marriage mela*
7. Emergency financial support and services.

* A social gathering of single/widowed HIV-positive men and women that serves as a venue for meeting potential seroconcordant partners.

Coordinating Services

Coordination and communication are fundamental to the ICP approach—ensuring that clients are linked to the necessary services, that efforts are not duplicated, and that all stakeholders in the care network carry out and are recognized for their roles in the network. Working with government program managers, clinical service providers, PLHIV organizations, and community-based organizations, the Avert Society helped each district revitalize existing monthly meetings. Stakeholders were already meeting routinely to discuss activities; the Avert Society used these meetings to refocus efforts on a specific issue. The Avert Society worked with partners to implement a traditional quality improvement approach in which participants shared data, identified challenges, devised easy and cost-sensitive solutions, and measured progress each month. Routinely collected data, including progress toward achieving enrollment goals and recovering those LTFU, were identified as a benchmark for overall program quality. The District AIDS Prevention and Control Unit (DAPCU) of each district was made responsible for reviewing the data from the previous meeting, summarizing achievements and outstanding issues, and sharing the latest data. However, it became the shared responsibility of all attending the meeting to address issues and to answer two critical questions: 1) How do each of the partners contribute to getting and keeping clients in care? and, 2) How do they recover missing clients as quickly as possible while addressing the reasons for the dropout? Participants develop concrete plans for increasing enrollment and addressing LTFU at the individual and program level. Plans detail responsibility for actual follow-up with specific partners and identify links to appropriate community programs, including those targeting high-risk groups.

Drop-in Centers: Linking People Living with HIV with Support and Service Delivery

The seven DICs supported by the Avert Society function as the networking centers of the ICP approach—linking each PLHIV with appropriate services while providing a broad range of support for individuals. Designed, managed, and operated by local organizations of PLHIV with technical and financial support from the Avert Society and other organizations, the DICs and their staff are central to the success of the integrated care approach, which connects clients not only with clinical, community, and home-based HIV services, but also with government schemes for related services. Each PLHIV network supported by the Avert Society provides a comprehensive set of client-centered public, NGO, or private-sector services (see Box 1). The district-level office of each network provides all of the services and supports activities at the taluka level (an administrative unit at the subdistrict level), as well as a limited amount of home-based care. All of the networks triage home-based services, prioritizing clients who have missed clinical appointments or are in need of emergency support, although the capacity of DICs to provide routine home care is limited, given the increasing number of clients.

Outreach: Outreach workers are a fundamental part of the response to HIV in Maharashtra, providing one-on-one and group counseling, addressing internal and external stigma, and serving as a critical bridge between clients and clinical and social service providers. Outreach workers, typically employees of PLHIV networks, are trained in three curricula (HIV Basics in 12 modules, Counselor Training, and Program Management) from the Avert Society and also receive on-the-job support from network and Avert Society staff.

In all of the five districts visited, network outreach workers routinely collaborated with a wide range of services and facilities, including the Link Worker Scheme (a rural outreach program), the prevention of parent-to-child transmission services, auxiliary nurse midwives, the condom depot, programs for children affected by HIV, and Integrated Counseling and Testing Centers, to ensure that clients are linked to appropriate and routinely available services, and that programs are not duplicating each other's efforts.

Links to government schemes: Besides routine outreach, the linkage between the networks and government schemes is a unique feature of the ICP. Beginning in Nagpur with NNP+ (Nagpur network of people living with HIV), the Avert Society systematically worked with stakeholders to set up a system of promotional camps that simplify enrollment in a variety of government schemes such as charity trusts, ration cards, below poverty line schemes, and the Sanjay Gandhi Niradhar Yojana financial assistance. Outreach workers work with clients beforehand to ensure that they have all the necessary papers and documentation available. On the day of the camps, the outreach workers help PLHIV navigate brief meetings with the scheme officials and submit the paperwork; if eligible, clients are enrolled immediately or within days of the camp. The government scheme camps are now being conducted in three districts, with districts sharing information so that they learn from one another.

Linking Clients to Decentralized Clinical Services

ART Centers are responsible for providing comprehensive HIV clinical care, but they are overburdened. Offering services at ART Link Centers closer to clients would achieve a number of important objectives—relieving the pressures on providers at ART Centers while reducing the burden on clients, particularly in transportation costs and lost wages. However, it was recognized that in order to be successful, PLHIV networks would need to be engaged in the process of decentralization. Working in collaboration with the DICs, outreach workers were placed in the ART Centers to guide clients to decentralized services and link them to services closer to their homes.

Results

The ICP very quickly achieved significant impacts, in terms of both service coverage and quality and life improvements among PLHIV. A large part of the initiative's success is its implementation through existing programs and structures, which also strengthens what were largely vertical programs. Results for specific program goals are summarized next.

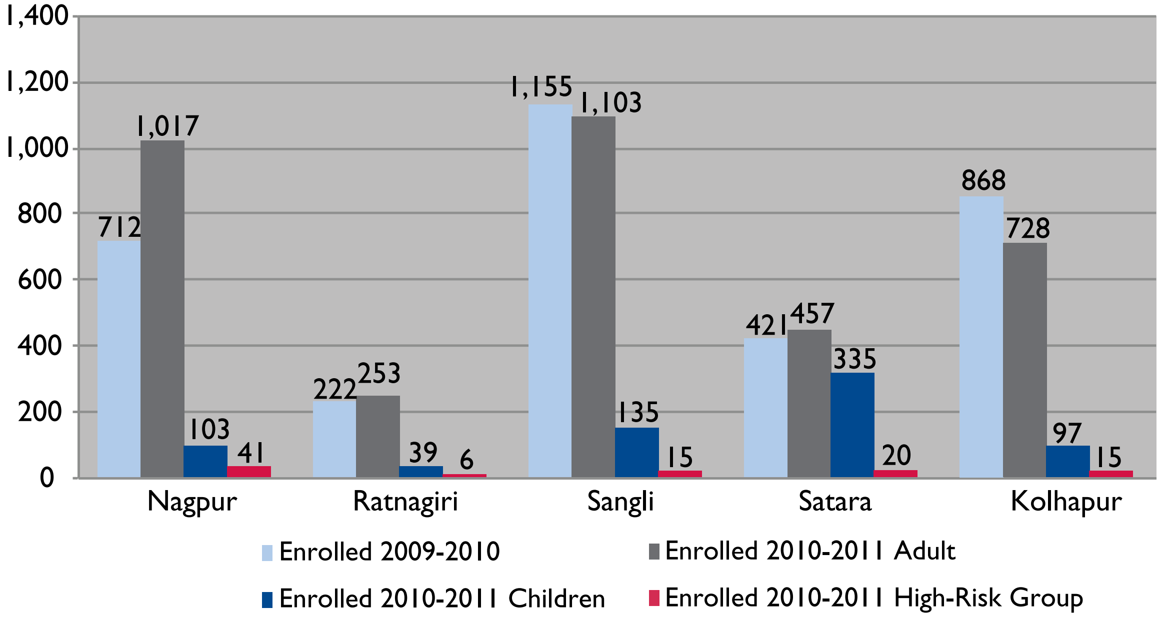
Increased enrollment in DICs: An important purpose of the ICP was to increase enrollment into the PLHIV networks by strengthening relationships with ART Centers, increasing the scope and depth of services, and decentralizing key functions.

To determine if this goal was met, enrollment data from the PLHIV networks participating in the ICP was analyzed, comparing data for the first year of implementation to historical data (see Figure 2).

It is clear that the ICP and DIC programs helped the networks to increase enrollment. Each district had set a goal of enrolling 500 new people into their DIC (except Ratnagiri, which set a goal of 200). All but one network surpassed the previous year's enrollment and all exceeded targets. A number of factors led to this result, including 1) placement of outreach workers from the DICs at ART Centers, which put PLHIV networks directly in contact with potential members and allowed them to steer clients toward the network; 2) the DIC's range of high-quality, client-centered, and comprehensive services that address clients' health and well-being; and 3) the addition of related services, such as linkage to government schemes.

It should be noted that one of the program's goals was to increase the enrollment of individuals from high-risk groups. Unfortunately DICs and ART Centers do not routinely collect information that allows the identification of individual clients as from

Figure 2. Enrollment in drop-in center programs by district



a specific high-risk group. Therefore, it was not possible to determine if this goal had been met, though program managers reported that they felt it had.

Reduced loss to follow-up: Besides increasing access to HIV care, a primary goal of the ICP was addressing LTFU among ART and pre-ART patients. Staff from the DAPCUs, ART Centers, and PLHIV networks realized that the situation required immediate, collaborative, and result-oriented attention. Data provided by the DICs as part of this review show that those efforts have paid off (see Table 1). This review focused on the DIC's LTFU interventions only, not those of other HIV service agencies such as ART Centers, which also have LTFU concerns for which DICs are not responsible.

Programs reported that the greatest challenge in contacting lost clients was incomplete information, an issue for approximately two-thirds of clients classified as LTFU. Key informant interviews revealed that for those clients for whom information was sufficient, the interval between LTFU and clients' return to care is typically less than one month, and in Kolhapur, DIC and ART Center staff reported that 70 percent of clients return to care within one week of outreach from DIC staff. Sangli and Ratnagiri were the only districts that reported challenges getting clients to return to ART Centers. In Sangli, the primary reasons for not returning to care was unwillingness of two groups, pre-ART clients and youth, to accept their HIV status. In Ratnagiri, three clients would not return to care because periodic stockouts made access to antiretrovirals (ARVs) unreliable.

Improved quality of life for PLHIV: Each DIC offers comprehensive social support programs to improve the quality of life of its members. The DICs report a significant increase in participation in self-help groups, pressure or advocacy groups, and income-generating activities, contributing to an improved quality of life for participants. Over 100 men and women who participated in focus groups reported decreased stigma and discrimination and increased autonomy as a result of their participation in ICP activities.

Improved linkages to government schemes: This linkage has proved to be an important program innovation. Districts where this initiative is implemented report increased enrollment in linkage programs, with particular success using promotional camps (see Table 2).

Over 1,000 PLHIV now have access to government-provided basic nutrition, housing, and economic support because of the ICP's enrollment activities, especially the promotional camps. Camp programs

Table 1. Resolution of loss to follow-up (April 2010–March 2011)

District	Reported LTFU	Transferred/ Died/ Incomplete information	Returned to care	Unresolved/ Not returned to care	LTFU rate (%)
Kolhapur	109	31	78	0	0
Nagpur	342	186	176	0	0
Ratnagiri	329	127	199	3	0.9
Sangli	600	298	200	102	17
Satara	298	210	88	0	0

Table 2. Government scheme enrollment

District	Attended promotional camp	Number enrolled from camps	Non-camp referral	Number enrolled (non-camp)	Total enrolled
Kolhapur	N/A	N/A	134	44	44
Nagpur	1,274	407	700	43	450
Ratnagiri	133	92	N/A	N/A	92
Sangli	1,101	101	523	396	497
Totals	2,508	600	1,357	483	1,083

were able to achieve significant impact because they entailed both preparing clients beforehand and engaging government scheme managers in intense discussion. In Nagpur and Ratnagiri particularly, the ratio of those reached to those enrolled was much greater for camp activities than for the non-camp approach.

Decentralized services: As a result of the ICP's efforts to decentralize the services and staffing of PLHIV networks, outreach workers reportedly spent more time in communities and less time at headquarters. This was due in part to the increased time they spent on LTFU visits and to working from office space in talukas. Also, all of the PLHIV networks reported increases in the number of volunteers trained to provide services and support at the community level, as well as increases in the number of new and continuing support groups, pressure/advocacy groups, and self-help groups.

During this period, enrollment in the ART Link Centers also increased, although in most cases enrollment goals were not fully achieved. Focus group discussions with clients and staff of the ART Centers identified two major reasons why clients do not switch from the ART Centers to the Link Centers: 1) concerns about confidentiality, status disclosure, and status within the community; and 2) the familiarity and comfort of existing relationships with ART Center staff.

What Worked Well

As described previously, the ICP's use of existing services and initiatives was critical to its success, facilitating rapid implementation and fostering change from within the system and the community. However, a number of related factors, described next, enhanced ICP's progress in effecting change.

Fostering leadership: The success of the ICP required the identification of champions that led integration efforts within and between each of the stakeholder groups. In each district, DAPCUs, PLHIV networks, ART Centers, Link Worker Schemes, and other partners identified a leader who was responsible for overseeing implementation of ICP approaches and services. Typically, this person was a senior staff person within the DAPCU, who had the authority and responsibility to bring together partners. It is important to select champions from within the government structure who have responsibility and authority, as well as status among the stakeholders. These champions were critical both to mobilizing internal resources to commit to this effort and to routinely communicating with their counterparts in other agencies. The ability of these leaders to both maneuver within their organizations and forge external partnerships helped create an environment that nourished the establishment and growth of the ICP. Also vital was the leadership from within the DICs, where a staff member was assigned to coordinate ICP activities.

Importantly, DAPCUs fostered leadership through a consistent approach that sought to forge multiple linkages, such as between public-sector providers and NGOs, and among a range of NGOs. DAPCU's leadership and clear articulation of the rationale for these linkages helped create an environment in which all of the partners feel their contributions are respected. NGOs, DICs, and other partners reported increased engagement and interest by DAPCU staff in their programs.

Supporting coordination: Monthly coordination meetings had a significant impact during the design, implementation, and monitoring of the ICP. There are several reasons why this coordination effort has worked so well. First, the monthly meetings were not new obligations added to the already busy schedules of providers; instead, the meetings were re-engineered to address current concerns. Second, participation in the meeting is multidisciplinary, including various levels of staff involved in client care and follow-up, including program managers, clinicians, counselors, and outreach workers. All participants are expected to participate in the meeting, to critically review data, and to provide input to solve challenges based on their unique position and viewpoint. Third, coordination meetings are also forums for capacity building and sharing information about changes in NACO policy and other emerging issues. Finally, the monthly meeting is not the only venue or opportunity to coordinate. In all the districts visited for this review, stakeholders reported weekly, and in some cases, more frequently. Coordination efforts focused on sharing information and ensuring a minimal duplication of effort, particularly in home visits to clients who have missed appointments.

> ***"The outreach worker has taught me to stand on my own to support my wife and children."***

Also, DAPCUs provide capacity building to NGOs and village government officials outside the monthly meetings.

Strengthening outreach workers: Under the ICP, the role of outreach workers was focused and integrated into the broader health system. Outreach workers now typically spend a part of every day at ART Centers providing assistance in a number of critical areas, including ensuring that clients move rapidly from testing sites to pre-ART visits, supporting patient navigation for non-HIV services including tuberculosis screening and intensive adherence counseling, and most importantly, playing a central role in the follow-up of ART and pre-ART clients who have missed clinical appointments. This new focus required a change in the scope of work for many outreach workers. Many outreach workers have begun delegating the management of self-help groups and routine group counseling sessions to clients, which allows the outreach workers to focus on their new responsibilities while building clients' skills.

Empowering PLHIV: The DICs initially offered a core group of activities, but added other activities to keep stride with clients' growth development and needs. Even though empowering clients was not a primary objective of the DICs, it was evident that the new activities enhanced clients' self-worth and confidence. Clients went from relying on the outreach workers to advocating on their behalf and taking on their own issues and those of their peers. This increased empowerment facilitated the formation of pressure groups that sought solutions for problems affecting individual PLHIVs (family issues) and groups (e.g., discrimination faced at the local clinic). As a client reported, "The outreach worker has taught me to stand on my own to support my wife and children." As a result, PLHIV are better able to deal with the negative self-image that often is part of living with HIV.

Another activity that evolved was income-generating activities. As many women became widows, they needed a way to support themselves. The DICs started income-generating activities, including microlending to start up women-owned businesses such as tailor shops and craft making. Men were not excluded from income-generating activities, and both men and women learned skills to make products that they could sell, or received loans to start up small businesses of their own.

Meeting the needs of children living with HIV: With its focus on providing family-centered care, the ICP required the development of services tailored to the unique needs of children living with HIV—a highly vulnerable and neglected group. DICs routinely offer self-help groups various services specifically for children living with HIV. During these sessions, counselors provide support on issues that affect children, including disclosure, bereavement, stigma, and discrimination. In Kolhapur, the DIC created a corner in the office where children can gather and play. This provides parents with a respite during visits and allows children to interact with other children who face similar challenges. Because a number of grandparents are responsible for the care of children living with HIV, routine home-based visits were identified as critical, both for supporting caretakers and providing one-on-one counseling to children.

Improving data for patient management and program monitoring: All of the DAPCUs have prioritized efforts to improve data collection and use. The use of monthly data has allowed programs to monitor enrollment more closely and to address challenges such as LTFU. Several districts are implementing innovations to address local needs. In Kolhapur, for example, the DAPCU developed its own electronic listing to address LTFU in near real-time, and sending the list out daily to organizations responsible for assisting with LTFU. Previously, Kshitij, the PLHIV network in that area, only received the LTFU list at the DAPCU monthly meetings. Now, the ART Center and the NGO can communicate daily, using a password-protected electronic system, about patients who did not attend the clinic. Outreach workers can then be sent out immediately to track them down, rather than waiting until the following month to receive the list from DAPCU.

Challenges

Limited geographic coverage of the ICP/DIC program: Although the ICP program made a significant impact in a relatively short period of time, it has been limited in part by its inability to reach entire districts. Currently, the ICP targets specific talukas in each district, using epidemiologic and program data to prioritize where services will be offered. This approach enables the program to establish a firm foundation and prioritize limited resources where the greatest impact could be achieved. However, significant unmet demand remains. Given current staffing levels, even with decentralization, it is not feasible for the current outreach workers to provide services to more talukas. Concerns about transport costs to reach more remote talukas also hamper efforts to expand the model.

Unmet needs of growing children: Although the ICP has been able to meet some of the needs of children living with HIV, more needs to be done. Staff have received training on serving youth, but it is inadequate to meet the complex needs of young girls and boys. More targeted training on the unique needs of children and adolescents living with HIV is required at all levels and among all stakeholders. Activities should include developing child-centered and adolescent information, education, and communication materials and age- and development stage-appropriate approaches to disclosure, sexuality, and adherence. The current programs and initiatives do not have the full set of skills and services needed to address the changing needs of this group. Also, most programs lack the materials and skills to build the capacity of parents and other adult caregivers to support children living with HIV as they transition to adolescence and adulthood. Lastly, clinical providers need training on giving appropriate support to children, particularly those on ARVs as they transition to adult regimens and become increasingly responsible for managing their own clinical care.

Evolving counseling needs: Counselors, outreach workers, and clients all reported the need for additional technical support to update counseling skills. As the HIV treatment program in India matures, the needs of clients are becoming more complex. Staff and beneficiaries mentioned immediate needs in three areas. The first area is regimen switching. Some PLHIV need to switch their HIV drugs for a number of reasons, such as temporary stockouts, side effects, or toxicity. Counseling messages need to be tailored to address the reasons for the switch, new dosing schedules, related dietary restrictions, and any side effects from the new drugs. The second need addresses second-line drugs, which are needed by an increasing number of PLHIV and, until recently, were unavailable in district ART Centers. Patients are usually moved to a second-line regimen because of a failure of the first-line regimen, either due to the viral strain or to adherence problems. As with regimen switching, counseling for second-line drugs must address side effects, dosing and dosing schedules, dietary restrictions, and an increased focus on adherence. Lastly, because PLHIV live longer as a result of improved clinical care and access to ARVs, new adherence approaches will be needed for long-term survivors.


Andrew Fullem

Patient support group, Guruprasad, Ratnagiri.

Meeting the needs of high-risk groups: According to Maharashtra's HIV epidemiological data, infection rates are significantly higher among high-risk groups; the ICP strategy was developed to meet the specific needs of these marginalized individuals. However, data from ART Centers, ART Link Centers, and DICs indicate that few people who self-identified as from a high-risk group utilize care and support services. So, although clients may be from high-risk groups, there is no way to verify this with the available data. The lack of client-level information about risk and environmental factors that may affect adherence, disclosure, stigma, and discrimination greatly limits the ability of programs to effectively meet the needs of clients. To minimize barriers to care and ensure that high-risk groups can receive maximum benefit from treatment, staff in all programs need to be able to gather more detailed information about clients' risk factors and to tailor adherence and prevention with positive programs to address those risks. Improved counseling skills for working with high-risk groups should be part of efforts to improve information gathering.

Continuing stigma and discrimination: PLHIV, outreach workers, and counselors all report a positive shift in stigma at the individual, household, and community levels as a result of their work. However, stigma in the health care system is widespread. Clients report accepting attitudes within the ART Centers and ART Link Centers, but when they move outside the protected confines of these programs, they are almost immediately faced with stigma and discrimination. This raises challenges to service access and makes it more difficult to meet clients' non-HIV health needs, including services for tuberculosis, obstetrics and gynecology, and oncology.

Continuing need for economic opportunities: Initial efforts to address the economic situation of PLHIV have succeeded. Entrepreneurs received loans to start businesses using established microfinancing approaches, and loan repayment appears to be on schedule. For income-generating activities to be sustainable, many participants need training in business management and marketing. Currently, the network provides these services directly. For these new businesspeople to reach their highest potential, linkages need to be made with other businesspeople or community leaders who can provide further training in business management. Also, PLHIV who are not participating in income-generating programs reported challenges in finding permanent employment in the formal sector. In most cases, the ICP and the networks do not have the resources or skills needed to broker employment with local businesspeople.

Future Programming and Recommendations

The ICPs are entering a transition period, with support for the PLHIV networks moving from the Avert Society to MSACS. A number of factors will have an impact on future programs. Some, such as ARV stockouts, will affect ICP's future directions, but are beyond the control of ICP program managers. The following recommendations focus on factors that DAPCUs and the networks can affect and apply.

Continue and expand ICPs: In just over a year, the ICP approach implemented by PLHIV networks, DAPCUs, and other stakeholders in selected districts in Maharashtra has been successful. The ICP should continue in the districts that are already implementing this approach, with an emphasis on continuing the support at the district and taluka level and expanding opportunities to provide similar services elsewhere, particularly in those talukas with significant numbers of PLHIV. Future directions should especially emphasize continuation of the monthly coordinating meetings and support to the PLHIV networks. DAPCUs should consider rotating the meeting location to highlight successes and concerns of programs in different parts of the district. While the transition of support for the PLHIV networks moves from the Avert Society to MSACS, all partners will need to monitor the situation closely.

MSACS and other State AIDS Societies should consider replicating the ICP approach of coordination, outreach, and service delivery across government and NGOs throughout India. State AIDS Societies considering replication should not overcomplicate the approach; the success of the ICP and DIC models has been mainly built on the re-engineering of existing structures to meet new needs and expectations. Ownership of the approach and outcomes has always rested with the DAPCUs and PLHIV networks, with targeted technical assistance from the Avert Society. Such an approach should be replicated in expansion efforts.

To remain relevant, PLHIV networks need to routinely assess client needs and develop interventions or linkages to address those needs. In the near term, a number of initiatives are needed, including ones that address 1) adolescent-focused HIV treatment and support services, 2) expanded economic and livelihood opportunities, and 3) stigma and discrimination at health care facilities. Also, ART Centers may consider working with DICs to revise the initial follow-up schedule for ART patients to create strong relationships with PLHIV and to reduce the likelihood of LTFU. Ratnagiri, for example, has devised schemes to develop stronger relationships with patients. Once a client enters pre-ART services, the ART Center schedules monthly visits for six months rather than a single six-month check-up. This allows patients to become familiar with the clinic and the staff, including the outreach workers, so that when they start ART they are used to going to the clinic regularly. Additionally, the ART Center in Ratnagiri places an emphasis on pediatric patients and sees them more regularly than required. One of the ways they do this is to schedule clinic dates to coincide with immunization days and wellness checks.

Establish national DIC standards: NACO has drafted the DIC guidelines and the Avert Society is advocating expediting the finalization including incorporating the lessons learned from the Avert Project; approved guidelines are needed to ensure standardization within districts and across India. In the meantime, the Avert Society and others have written and implemented standard operating procedures using the draft documents as a guide. Going forward, it will be important for NACO to clearly articulate the vision, mission, and scope of services for DICs. The final guidelines should allow states sufficient flexibility to adapt the approach to meet local context, but should also clearly outline both the process and the expected outcomes against which program performance will be measured.

Once the guidelines are approved, NACO and State AIDS Societies should develop technical assistance guidance on the rollout of the DIC guidelines and expectations for service contracting.

Address the needs of high-risk groups: Programs need to increase their focus on improving the ability of ART Centers, ART Link Centers, and DICs to assess and meet the needs of high-risk groups. Client profiles and risk assessments need to be carried out routinely to gather information about each client's risk-taking behaviors and personal environment to develop appropriate, individualized care plans.

Support second-generation training: As the ICP matures, clinical DIC staff will need additional training on emerging technical areas, including regimen switching, second-line drugs, adherence support for long-term survivors, and the transition of children to adolescent and adult HIV care. PLHIV network staff will also need training on the emerging roles of outreach workers in supporting decentralized PLHIV groups, which might include skills in the training of trainers, conflict resolution, and consensus building.

Continue decentralization: It is critical for MSACS, DAPCUs, and PLHIV networks to continue decentralization by increasing the use of ART Link Centers, which will both ease the burden on already overworked clinical staff at ART Centers and reduce some of the economic burden placed on clients. A unique facet of the current program is that the decision to be seen at the ART Link Center is ultimately left to the client. To the extent possible, this should remain the case. This will require staff from ART Centers, ART Link Centers, and PLHIV networks to address client concerns about patient confidentiality. Unless clients feel their privacy can be protected, many are unlikely to seek out care in facilities closer to their home, regardless of cost savings. Also, strategies that link community, tuberculosis, and HIV programs, such as the one in Kolhapur, should be supported and encouraged in other settings.

The PLHIV networks have made great strides in decentralizing services, resulting in even greater patient autonomy and self-reliance. These efforts should continue and PLHIV self-help groups and pressure groups should become increasingly autonomous. Programs should also consider strategies that engage PLHIV in LTFU efforts. Also, PLHIV networks need to engage MSACS in a conversation about how to offer services in more talukas given the increased demand and the stresses on existing providers.

Strengthen the linkages with government schemes: Linkages to government schemes contribute significantly to the comprehensive services offered by DICs. As these efforts go forward, attention to a number of critical activities is crucial. First, DIC and ART Center staff should receive formal training and should participate in information sessions about the scheme requirements, which is ideally led by the municipal or government managers responsible for oversight of the schemes. Also, PLHIV network staff need to cultivate and maintain a relationship with public-sector managers to stay current about changes to scheme requirements. Lastly, network and government scheme staff in districts or states considering similar ventures should visit the districts that are already implementing such programs. During the development of the ICP in Maharashtra, these visits provided invaluable lessons on design, implementation, and monitoring.

Discretionary funds: The PLHIV networks play a critical role in improving their clients' quality of life. The funding for most of the project activities such as the DICs and Link Worker Schemes comes through grants supported by the Government, the Global Fund to Fight AIDS, Tuberculosis and Malaria, and donors like USAID. Several of the networks also have discretionary funds available to meet clients' emergency needs, including funeral expenses, but typically these and other kinds of noncore services must draw on other revenue schemes. Networks should receive support to enable them to carry out fundraising to create a pool of unrestricted funds. In Ratnagiri, the PLHIV network Guruprasad has a fundraising strategy that includes but goes beyond direct donations. The organization sponsors an annual concert; income from this event may be used to cover clients' emergency needs as well as activities that are not supported by other donors. ■

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ACKNOWLEDGMENTS

AIDSTAR-One would like to thank the staff of the Avert Society who generously provided their time and insights in the development of this case study, particularly Leena Rane, Anjana Palve, and Anna Joy. AIDSTAR-One would also like to thank the staff, volunteers, and clients of the drop-in centers who contributed significant time and insights into their programs and the impact on the lives of people living with HIV. Thanks also to Elizabeth Berard with the U.S. Agency for International Development (USAID)/Washington for her review of the case study. Finally, the authors would like to thank the USAID/India Mission for its support and guidance, including Sanjay Kapur and Sangeeta Kaul, and to Sampath Kumar for his technical review and editing.

RECOMMENDED CITATION

Fullem, Andrew, and Jamine Peterson. 2012. *Integrating HIV Care: Improving Programs, Improving the Lives of People Living with HIV*. Case Study Series. Arlington, VA: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.

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