

## ICTs and the fight against HIV/AIDS in India

India accounts for 68% of the South Asian HIV epidemic and ranks second only to South Africa in the total number of people living with HIV according to the recent estimates (NACO, 2004). The crisis has spawned initiatives from a variety of sectors including the central government, state agencies, non-profit organisations, local, regional and national networks of HIV positive people, international agencies and corporations.

While over 1200 agencies from multiple sectors have responded to the HIV/AIDS crisis, several needs have to be met in order to mount an effective nationwide response. Primary among these are (i) the pressing need for dialogue, networking and coordination among the various implementing agencies and other stakeholders in the fight against this epidemic and (ii) The need for accurate information delivered in a timely manner; for instance, treatment updates that have immediate implications for people living with HIV/AIDS, or prevention research updates that dictate intervention priorities and inform policy.

SAATHII (Solidarity and Action Against the HIV Infection in India) was launched in 2000 to facilitate dialogue among the diverse sectors involved in the fight against HIV/AIDS in India. Its activities have since expanded to include a range of capacity-building initiatives such as facilitating network-formation, mapping of resources and services, and information dissemination and technical assistance to service providers. In addition, SAATHII hosts the India satellite meetings at international AIDS conferences and is involved in advocacy for various treatment, support and care issues.

### SAATHII and ICTs

SAATHII was among the first non-profit organisations based in India to use ICT tools in the HIV/AIDS area. We have been working to bridge information, networking and other capacity gaps through three main avenues.

[saathii@yahoogroups.com](mailto:saathii@yahoogroups.com)

The listserv [saathii@yahoogroups.com](mailto:saathii@yahoogroups.com), started in 2000, addresses the need for timely information delivery. The listserv daily posts features covering current advances in behavioural research, basic science and clinical aspects of HIV/AIDS that are relevant to resource-limited settings. The listserv is the best recognised public face of SAATHII, providing daily access to scientific, advocacy, and care-support-treatment news for over 1675 people. The listserv also contributes to programme development by connecting implementing and funding agencies with each other; and enables greater participation of representatives from a variety of sectors at HIV conferences and policy meetings.

### *Directory of HIV/AIDS organizations*

SAATHII has published an online version of SAATHII Red Ribbon Pages 2003, the first national HIV/AIDS directory developed for India. This searchable database has contact information and service descriptions for over 1150 implementing, funding and policy organisations. The directory is accessible at <http://www.saathii.org/stapps/searchIndex.jsp>. The design and implementation of the online directory was a collaborative effort between SAATHII and TransLucent Software Solutions and Services, Chennai. Data collection for an updated edition has just been completed.

The directory allows the public to find out about HIV/AIDS resources, including drop-in centres, counselling, and testing and treatment services in their vicinity. Evidence from feedback forms and personal interviews indicates that

the directory is proving extremely useful in facilitating partnerships among HIV/AIDS service providers, by enabling knowledge sharing and referrals. Finally, the directory is helping policy and funding agencies in identifying geographical and programmatic gaps in service delivery. Over 1200 implementing organisations, including government and nongovernmental agencies, hospitals, and positive networks serving an estimated 200,000 people infected with or at risk of contracting HIV, are now using the SAATHII directory in its electronic or print versions. This directory constitutes SAATHII's most significant contribution to date.

[www.saathii.org](http://www.saathii.org)

The website [www.saathii.org](http://www.saathii.org) was created to serve as a clearinghouse of information on HIV/AIDS in India. Web hosting space is donated by Computech Enterprise Solutions. Now 2 years old, the site contains over 450 electronic pages of information. Some of its highlights are:

- Educational resources for vulnerable populations such as intravenous drug users, migrant workers, pregnant women and the MSM communities;
- Scientific articles and research up-dates on various aspects of HIV/AIDS relevant to India and Asia-Pacific and complete bibliography of the articles & abstracts published on India;
- Guidelines on HIV/AIDS prevention, care, support and treatment issued by National AIDS Control Organisation (NACO), UNAIDS, World Health Organisation (WHO) and other agencies;
- Summaries of national and international conferences and civil society consultations;
- Information on Indian and international funding bodies and guidelines for applications for grants from these institutions;
- HIV/AIDS related jobs, conferences, workshops and training programs in India and abroad;
- The online directory of HIV/AIDS agencies; and
- Links to e-mail discussion groups and other relevant information.

There is qualitative evidence that [saathii.org](http://saathii.org) has become indispensable as a source of information on HIV/AIDS for activists, volunteers, NGO program personnel, funders and policy makers. Through its website, mailing list and resource directory, SAATHII has managed to network effectively with most of the civil society agencies that are working against HIV/AIDS in India.

### **Lessons learnt**

We offer the following caveats on the role and/or feasibility of ICTs. These are based mostly on SAATHII's experiences in information dissemination, and on discussions with NGO personnel met during training programmes, networking forums, site visits and other offline events.

#### *Language limitations*

Currently, most HIV/AIDS information available in electronic formats is in English. This restricts the reach of information among NGO staff and can reinforce existing power structures within and across NGOs in India. Conscious efforts need to be made within NGOs to disseminate information to all concerned in their organisations, including translation where needed. It is mostly outreach workers and peer educators who are in direct contact with target populations, and who know most about the complexities in the field. It is vital that information reach them and also that they have an opportunity to share their field experience with a wider audience. Knowledge flow in both these directions can be limited by language, and the onus is on supervisory staff, information dissemination agencies, policy makers and funders to bridge this divide.

#### *Limited Internet access*

Even though many HIV/AIDS agencies have access to computers in the office and internet access at cyber-cafes, internet connectivity within agencies can be hampered by costs of telephony. There is scope for print dissemination of electronically received information accessed by larger agencies to other (especially smaller, rural) agencies in the form of newsletters and bulletins.

### Staff limitations

In our own work we have encountered challenges of finding trained staff to work as information management specialists and web developers. Professionally trained staff in these areas tends to get, and opt for, higher-paying jobs than are available in most of the NGO sector.

### Ethical considerations

While ICT has great potential for scaling up information dissemination and sharing, its efficacy and cost-effectiveness in prevention, knowledge-growth and other areas must be clearly understood. Resource allocation towards ICT should not conflict with more direct resource needs such as costs of medical treatment, which remain prohibitive for the majority of people living with HIV/AIDS in India. Negative attitudes of HIV/AIDS service providers towards ICTs in other resource constrained settings have been shaped largely by the apprehension that funding for ICTs will take away from direct services such as health care (Bateson Consulting, 2002).

### Future activities

Despite all types of constraints, ICTs do hold promise in certain areas.

**Table1: Primary needs of HIV/AIDS agencies in India**

Information, Education, and Communication-related needs	<ul style="list-style-type: none"> <li>• counselling-related skills, training and information</li> <li>• training in monitoring, evaluation and programme development</li> <li>• training in HIV/AIDS basics</li> <li>• training in issues of vulnerable groups (women, sexual minorities, children and adolescents, commercial sex workers, intravenous drug users, migrant populations, people living with HIV/AIDS)</li> <li>• training in specialised topics (alliance- building, fund-raising, communication and personality development).</li> <li>• funding to develop IEC capacity</li> </ul>
Human Resources	<ul style="list-style-type: none"> <li>• funding for additional personnel</li> <li>• needs for specialised personnel (eg. MSW)</li> <li>• training and updates on management and administration topics not specific to HIV/AIDS</li> <li>• support services for staff (eg. team building, conflict resolution, avoiding burnout).</li> </ul>
Infrastructure	<ul style="list-style-type: none"> <li>• funding for purchase or maintenance of infrastructure</li> <li>• equipment (including vehicles, medical/lab and office equipment, patient-oriented supplies)</li> <li>• physical space (including buildings, labs)</li> </ul>
Support for Programmes and Services	<ul style="list-style-type: none"> <li>• funding for initiating or sustaining programmes</li> <li>• technical support for programmes and services (including prevention, care/support, income-generation, life -skills and unspecified capacity-building programmes)</li> </ul>

**Note:** This information has been compiled from questionnaires distributed via the SAATHII website and postal mail.

(Sample size = 763)

#### *E-trainings*

SAATHII has worked at the ground level with rural, semi-urban and urban HIV/AIDS service-providing agencies, primarily in eastern and southern India, to build their capacities in areas ranging from organisational management and proposal writing to training on Prevention of Mother to Child Trans-mission (PMTCT), gender and sexuality, care, support and treatment, nutrition, sexual health, data analysis, documentation and evaluation. With a view to developing SAATHII's capacity-building outreach, a team of volunteers and staff are in the process of systematically assessing needs of HIV/AIDS agencies. Some of these needs are listed in Table 1.

Technical assistance outreach to NGOs in several of these areas can be enhanced using ICTs in combination with on-the-ground initial needs assessments and ongoing monitoring activities. SAATHII is embarking on a project using ICT to offer training to NGOs in rural and semi-urban areas. If successful, such e-trainings will allow us to increase the scale of our training programmes, in a cost-effective manner by reaching out to a larger number of organisations than is logistically possible with our current (offline) training programmes.

#### *E-forums for knowledge-sharing and advocacy*

SAATHII is in the process of identifying HIV/AIDS health-care providers (e.g. physicians with HIV treatment experience, counsellors, prevention experts) who would be willing to share their knowledge and experience with others through specialized community e-forums to be hosted on our website. We also hope to host similar e-forums for advocacy on such issues as treatment access.

#### *Data capacity building*

Another programme under development, led by the Dharani Trust (Bangalore) in collaboration with SAATHII and Servalots Infotech (P) Ltd., (Bangalore) is DataMatters, an initiative to enhance the data capacity of NGOs using the Pantoto Communities model. DataMatters focuses on technical support to NGOs to collect, organise, interpret and share data. NGOs working on targeted interventions for HIV/AIDS will be the focus of the first DataMatters initiative.

**Table 2: Information needs assessment: most common requests**

<b>Request</b>	<b>Stakeholder Category</b>
Local and Regional resources - services available and costs where applicable: inpatient, outpatient, counselling, private and public including primary care centres. This information should be available on website, by phone inquiry and at an accessible physical location.	NGOs, People Living with HIV/AIDS (PLWHA)
Tamil language IEC materials - online and offline.	NGOs
Resources and updates on treatment and support- local availability, opportunistic infections, side-effects, drug-interactions, nutritional requisites.	Doctors, Nursing faculty, PLWHA, NGOs
Basic sex/sexuality education as a precursor to HIV/AIDS information.	School students (Class XI and XII, both boys and girls)

#### *Local and regional HIV/AIDS information resources*

There is dire need for gathering and disseminating information on local and regional resources for the continuum of care, local language materials and knowledge support to local HIV+ networks.

Table 2 lists key results of an information needs assessment carried out with NGOs, HIV positive people and other stakeholders in Coimbatore and Madurai, Tamil Nadu.

The two AIDS InfoTech Centres established by APAC (AIDS Prevention and Control Project) in 1999 are stepping up efforts to meet these and other documented information needs in Tamil Nadu, deploying ICTs such as their mailing list and websites. ([www.mmhrcaidsinfo.org/](http://www.mmhrcaidsinfo.org/) and [www.psgaidsinfo.org/](http://www.psgaidsinfo.org/)). Such regionally focused efforts need to be initiated around the country.

## Conclusion

SAATHII's experience with the listserv, online database and website suggests that ICTs can facilitate many components of the capacity-building mission such as information dissemination, networking and advocacy. Further, there is potential for using ICTs to scale up technical assistance activities to HIV/AIDS service providers, as has been demonstrated elsewhere by recent research in prevention intervention training and knowledge transfer programmes (Kelly et al. 2004). Limitations of access such as language and internet connectivity dictate that ICT-enabled programmes be combined with other (lower-tech) modes of information delivery, exchange and networking.

## Acknowledgements

We are thankful to all the staff and volunteers of SAATHII who have contributed to this article. It is written by L. Ramakrishnan.

## References

Bateson, D. S., Consulting Inc. 2002 draft. Health, HIV/AIDS and Information and Communication Technologies: A Needs Assessment. Online at [http://www.voxiva.net/objects/pdfs/health\\_hiv\\_aids\\_ict\\_report.pdf](http://www.voxiva.net/objects/pdfs/health_hiv_aids_ict_report.pdf)

Kelly, J. A., A. M. Somlai, E.G. Benotsch, T. L. McAuliffe, Y. A. Amirkhanian, K.D. Brown, L.Y. Stevenson, M. I. Fernandez, C. Sitzler, C.Gore-Felton, S.D. Pinkerton, L. S.Weinhardt, K. M. Ogenorth, 2004. Distance Communication Transfer of HIV Prevention Interventions to Service Providers. *Science* 305: 1953-1955, 2004.

NACO, 2004. A note on HIV estimates 2003. National AIDS Control Organisation, New Delhi, India. Online at <http://www.nacoonline.org/facts.htm>

SAATHII, 2003. SAATHII Red Ribbon Pages: a directory of HIV/AIDS organisations in India. Solidarity and Action Against the HIV Infection in India, Chennai, India. Online at <http://www.saathii.org/stapps/searchIndex.jsp>

**Courtesy:** SAATHII, an Indian NGO.

---

<http://uk.oneworld.net/article/view/108250/1/1962>