

# HIV/AIDS counselling, just a phone call away



Four case studies of  
telephone hotline/helpline  
projects



Joint United Nations Programme on HIV/AIDS

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Cover photo:  
Poster from the Beyond Awareness Campaign  
of the South African AIDS Helpline

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*Geneva, Switzerland  
2002*

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- Helena Joseph (The National AIDS Hotline of Trinidad and Tobago)
- José Narciso Melchor C. Sescon (Remedios AIDS Foundation, Inc.)
- Radhika Chandiramani (TARSHI: Talking about Reproductive and Sexual Health Issues).

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## Acronyms

AIDS	Acquired immunodeficiency syndrome
AIDSCOM	A sub-agency of the Washington, DC Academy for Educational Development
ANC	Antenatal clinics
AusAID	The Australian Government's Overseas Aid Program
BAC	Beyond Awareness Campaign
CAREC	Caribbean Epidemiology Centre
CLI	Caller line identity
GTZ	German Technical Corporation
HIV	Human immunodeficiency virus
IDU	Injecting drug user
JHU-CCP	Johns Hopkins University Centre for Communications Program
MoH	Ministry of Health
NACO	National AIDS Control Organization
NGO	Nongovernmental organization
PAHO	Pan American Health Organization
PLWHA	People living with HIV/AIDS
RAF	Remedios AIDS Foundation
STI	Sexually transmitted infection
TARSHI	Talking about Reproductive and Sexual Health Issues
USAID	US Agency for International Development
WHO	World Health Organization

# Introduction<sup>1</sup>

Telephone helplines (also known as hotlines<sup>2</sup>) are telephone lines set up to take calls from people seeking information on specific topics—such as (in the case of this Best Practice study) HIV/AIDS. Four programmes were chosen to illustrate the Best Practice criteria for helplines: the AIDS Helpline of South Africa’s Department of Health, the reproductive health and sexuality helpline offered by a New Delhi-based nongovernmental organization (NGO) called Talking about Reproductive and Sexual Health Issues (TARSHI), the National AIDS Hotline of Trinidad and Tobago, and the hotline run by Remedios AIDS Foundation of Manila, the Philippines. Together, they illustrate the principles that make helplines so successful in providing HIV/AIDS information and counselling, the challenges helplines face, and the creative approaches that can be taken to meet those challenges.

## A brief history of helplines

Helplines are a relative newcomer among public health education services, having first appeared in the United States of America in the 1960s to facilitate access to social services by traditionally underserved populations. Helplines expanded throughout high-income countries in the 1970s to provide education and counselling on a wide range of controversial issues such as rape, drug use or suicide. By the early 1980s, when HIV/AIDS first emerged, helplines were already well established as a means of communication and offering support. The earliest HIV/AIDS helplines started in American cities where the disease first appeared—San Francisco and New York—and were operated by, or targeted, the gay community. HIV/AIDS helplines grew directly out of community need and were among the first initiatives organized by people with HIV/AIDS in response to the epidemic. By 1989, at the First European AIDS Hotline Conference, it was noted that helplines in high-income countries usually endured and grew “to the extent that the value of hotlines is now beyond any doubt in those communities where they have been established”<sup>3</sup>.

<sup>1</sup> This introduction was adapted from: Borden L, “HIV/AIDS telephone helplines: An under-utilized force for HIV prevention,” Masters Essay, Behavioral and Community Interventions, the Johns Hopkins School of Hygiene and Public Health, 2001. Additional information from: “Reaching adolescents through hotlines and radio call-in programs,” Focus on young adults, the In FOCUS series, [www.pathfind.org/focus/htm](http://www.pathfind.org/focus/htm).

<sup>2</sup> In most cases, the words ‘helpline’ and ‘hotline’ are used interchangeably. American English appears to use hotline more frequently, whereas British English uses helpline. This document will use both, reflecting how the organization being profiled refers to its own service.

<sup>3</sup> Comments by David Miller at the opening ceremonies of the First European AIDS Hotline Conference, Conference report from the First European AIDS Hotline Conference held April 1989 in Amsterdam. Since 1991, however, there have been few large-scale international workshops or conferences specifically addressing the issues facing helplines.

Despite their excellent track record, helplines expanded into low- and middle-income countries only within the past decade. Three of the helplines profiled here are elders among their peers: Trinidad's Aidsline was established in 1988, the Remedios project began in 1991, and a precursor to the current South African helpline began in 1992. TARSHI's project was established in 1996. The telecommunications infrastructure has been a principal obstacle to expanding helplines; in most low- and middle-income countries, people do not have access to a private telephone. In 1998, the United States of America had approximately 66 main telephone lines per 100 inhabitants. In contrast, sub-Saharan Africa (excluding South Africa) had approximately one for every 200 people, and access to public phones is similarly restricted, with about one for every 15 000 people, compared to a world average of one to 600<sup>4</sup>. Many Asian countries also have relatively limited telephone infrastructures. The rapid international growth of mobile cellular phones, however, may make it possible to bypass the development of fixed lines, so that countries can rapidly expand telephone access to large segments of their populations. As low- and middle-income countries improve their telecommunications infrastructure and identify HIV/AIDS as a pressing social concern, telephone helplines are expected to increase.

Around the world, programmes operating helplines largely share similar goals and functions, although they may emphasize them differently and provide different models of service. The primary functions of helplines are 1) to provide information; 2) to offer support and counselling; 3) to make referrals to other agencies; and 4) to feed back data to the government or other agencies as a way of tracking the impact of communications campaigns.

Telephone helplines share some characteristics with other outreach techniques, such as mass media campaigns and peer education, and can work synergistically with them. For example, like mass media campaigns, helplines can reach large numbers of people and, like peer education, can offer a personalized service that responds directly to an individual's concerns and questions. Unique to the helpline service is "the confidential, one-to-one, anonymous contact that callers have with counsellors [which] allows for difficult and awkward questions about

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<sup>4</sup> Jensen M, 'Policies and Strategies for Improving Africa's Information and Communications Infrastructure.' Power Point presentation at the African Development Forum 1999 held in Ethiopia, slide 4.

personal sexual behaviour and sexuality issues ...”<sup>5</sup>. Unlike face-to-face counselling, helplines allow callers to interact at their own convenience and to remain in an environment of their choice. This anonymity is especially valuable in situations where frank discussion of sexuality challenges cultural norms and taboos, as well as wherever HIV carries a strong stigma. People need not fear that their HIV status would be questioned or exposed by calling a helpline. Most helpline services have established ethical principles that guide their counselling work and serve as the foundation of their programme. The National Hotline of Trinidad and Tobago, for example, has identified confidentiality, compassion and understanding, being non-judgemental, and providing up-to-date, accurate information as the basis of their service.

The HIV counselling offered by helplines is designed specifically to enable individuals to discuss the advantages of getting tested and how to change their risky behaviour—e.g., to adopt safer practices with respect to sex and/or injecting drugs. Telephone helplines operate on the assumption that “a key to changing attitudes and behaviours is the provision of factual, consistent and understandable information about HIV and AIDS by persons and organizations in whom the recipient has confidence”<sup>6</sup>. The challenge for a good counsellor is to elicit enough information about a caller’s behaviour and what influences it to offer information and support in a way that will be ‘heard’. Because callers often need more information or services than a helpline can provide, making referrals to testing facilities, support groups or other kinds of social and medical services is also a crucial component of helpline work.

Helplines that focus on HIV/AIDS are widely available throughout the North and are increasingly available in low- and middle-income countries. In 2000, when UNAIDS made an effort to assess the number of active HIV/AIDS helplines in such countries, 92 could be confirmed. The World AIDS Campaign 2001 prepared a directory of counselling helplines worldwide, which is available at <http://www.unaids.org/wac/hotline/index.html>

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<sup>5</sup> Stratten K, ‘An overview of national and international HIV/AIDS and social support helplines’. Paper prepared for the Beyond Awareness Campaign of the HIV/AIDS and STD Directorate of the South African Department of Health. March 1999, p.2.

<sup>6</sup> Waller R, Lisella L, ‘National AIDS Hotline: HIV and AIDS information service through a toll-free telephone system’. Public Health Reports; November–December 1991. Vol. 106, No. 6, p.628–634.

# The South African AIDS Helpline

## South Africa

Surface area (square km)	1.22 million
Total population	42 million
Urban population	50.1%
GDP per capita (PPP* US\$)	8908
Life expectancy at birth (years)	53.9
Infant mortality rate (per 1000 live births)	54
Adult literacy rate (>15 years)	84.9%
Adult HIV/AIDS prevalence (15–49 years)	19.94%
Adults and children living with HIV/AIDS	4.2 million
Telephones (mainline and cellular, per 1000 people)	270
Internet hosts (per 1000 people, year 2000)	8.4

\* Purchasing power parity

Estimated figures from 1999, where nothing else is indicated.

Sources: *Human development report 2001*, UNDP.

*Report on the global HIV/AIDS epidemic, June 2000*, UNAIDS.

*World development report 2000/2001*, World Bank.



## **HIV/AIDS in South Africa**

**S**outh Africa faces a serious and growing HIV/AIDS epidemic and, with an estimated 4.2 million people living with HIV/AIDS, South Africa has the largest number of people living with HIV/AIDS in the world. In addition, at the end of 1999, South Africa was home to 370 952 children under the age of 15 years, who had lost their mother or both parents to AIDS since the beginning of the epidemic. The epidemic is expanding rapidly. National sentinel surveillance surveys of antenatal clinic attendees have been conducted since 1990, and HIV prevalence among clinic attendees increased from less than 1% in 1990 to a median of 24.8% in 2001. Syphilis levels have, however, declined over the past three years, from 7.3% in 1999 to 2.8% in 2001.

The burden of caring for orphans and the ill increasingly falls on families and communities. Very limited HIV testing services have been available since the early 1990s. However, expanded voluntary counselling and testing (VCT) services are being introduced in 2002. The health services are overburdened in terms of caring for HIV/AIDS patients, and community-based and home-based care programmes are under-resourced. Similarly, limited resources exist for children orphaned or abandoned as a result of HIV/AIDS.

In comparison to other African countries, South Africa has a well-developed communications infrastructure and good access to the mass media. The country has also implemented the distribution of free condoms, mainly through public sector clinics, and the syndromic management of STIs. The rights of people living with HIV/AIDS (PLWHA) have been entrenched in various laws. For example, the right to privacy, including privacy related to HIV status, is protected by the Constitution. The Employment Equity Act prescribes that employees and/or job applicants may not be discriminated against on the basis of their HIV status, and neither employees nor job applicants may be required to undergo HIV testing. The Labour Relations Act protects employees from dismissal on the basis that they are HIV-infected.

Numerous surveys have demonstrated high levels of awareness of HIV/AIDS nationally, and there are clear indications that young people have adopted preventive practices. A 1999 sentinel site survey of young people conducted by the Beyond Awareness Campaign (BAC) of the Department of Health showed that condoms were widely accessible and that 52% of those who were sexually active (non-cohabiting) had used

a condom the last time they had sexual intercourse. Other recent studies have shown similar levels. The average age of first intercourse was 15.7 years for males and 17 years for females.

## **Telecommunications overview**

South Africa's well-developed telecommunications infrastructure means that a telephone helpline can reach significant numbers of people. Approximately 36% of households have access to a telephone/cellular phone and an additional 38% have access to a telephone/cellular phone within a 15-minute radius. The lack of reliable landline services has contributed to the recent rapid growth in the cellular phone industry, in which some 90% of new connections have been made to 'pay-as-you-go'-type services. This has expanded telephone accessibility to individuals with low incomes who previously could not have afforded a fixed-line phone<sup>7</sup>.

This significant growth in telephone access over the past five years has shifted the potential of the helpline from a service that favoured single-language elites to one that could be promoted to all communities on a national basis.

## **A brief history of the AIDS Helpline in South Africa**

The Department of Health initiated the AIDS helpline in 1992 and contracted the service to Life Line, a national NGO (which also managed a national personal crisis helpline), to conduct the service. The helpline was established and has always operated as a toll-free service, although it was not widely promoted or utilized in the early years of operation<sup>8</sup>. This was also a period of political change in South Africa, with the post-apartheid government being established in 1994. Up until 1997, the AIDS helpline was a relatively low-key resource, largely because the budget available to the service was small, HIV prevalence levels were low, and the objectives did not include the provision of multilingual service. Telephone access among the poor and politically marginalized was also limited. However, as the AIDS epidemic escalated and levels of awareness increased, it became clear that the helpline was a vital resource.

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<sup>7</sup> A cellular phone call to a toll-free line is none the less charged by the minute (although calls from call boxes are not). This might be a disincentive to use a cellular phone for a helpline call, although many queries can be handled relatively quickly. It would be possible, using call-centre technology, to track the number of cellular phone calls to the helpline, and this might be worth investigating.

Initially, the service operated via a complex system of five regional loops, with the national telecommunications service provider connecting calls to different regional Life Line centres on a rotating basis. Volunteer counsellors managed calls 24 hours a day and provided basic information, counselling and referrals to local organizations for condoms, counselling and testing, clinical services and other related face-to-face support.

In 1997, the Department of Health initiated a comprehensive ‘Beyond Awareness’ communications campaign, which had as its mandate the development of action-oriented approaches to HIV/AIDS prevention, care and support. This approach favoured communications activities that encouraged dialogue, and it was clear that the AIDS helpline would form an important cornerstone of this strategy.

During 1997/98, the campaign used mass media advertising to promote the line, and worked in collaboration with Life Line to monitor the response. The AIDS helpline number was also incorporated into the national red ribbon logo by the campaign.

But, as the volume of calls to the helpline escalated, a number of limitations to the existing system and organizational structure emerged. These related largely to the correlation between limited funding, unsophisticated technical management systems and increased demand. Constraints included:

- limited capacity, with only six incoming lines, which contributed to a high rate of failed calls (up to 75%) due to the line being busy;
- failed calls as a result of the line not being connected to the correct centres at the correct time—a responsibility of the telecommunications service provider;
- inconsistencies in training for volunteer counsellors;
- inconsistencies in responses to callers’ concerns;
- limited multilingual capacity;
- lack of clarity regarding the status of various services and their capacities to handle referrals;

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<sup>8</sup> The limited promotion was due largely to the early processes of technically establishing the line, along with the fact that such promotion was not centralized within communication programmes at the time.

- high turnover of volunteer counsellors;
- inconsistencies and complexity in monitoring the service; and
- insufficient funding and poor funding mechanisms.

Following a 1999 review of the service, a task team, including representatives from the Department of Health, BAC and Life Line, examined criteria for revising the helpline service. A number of criteria were identified, including:

- the need for technology that could cope with increasing demand;
- consistent and appropriate counsellor training;
- shifting from volunteer to salaried counsellors;
- appropriate counsellor debriefing and supervision;
- reducing the complexity of the monitoring systems; and
- developing an appropriate funding model.

Following these discussions, it was clear that a strategy would have to be developed for expanded funding of the service as well as for technical assistance. Technical assistance and funding were provided by Johns Hopkins University Center for Communications Programs (JHU-CCP) and USAID, with additional assistance and financial support provided by staff of the BAC.

The new model incorporated a centralized 24-workstation call centre located in Johannesburg, supported by technology that allowed for call holding, call allocation to specific counsellors, tracking of calls, on-line supervision and monitoring, and overall monitoring of call data. The plan included the recruitment of paid counsellors and supervisors, and the expansion of the management team.

### **Goals of the programme**

The current overall goal of the programme is to provide a multilingual, readily accessible service that operates 18 hours a day. The objectives include: 1) providing basic HIV/AIDS information; 2) providing telephone-based counselling; and 3) referring callers to appropriate services (e.g., face-to-face counselling, condom distributors, VCT services and clinical services), where applicable.

## Major elements of the project

### Collaboration and funding

Prior to the development of the centralized call centre, funding had largely been directed through the Department of Health's nongovernmental organization funding programme, but the programme's budget limitations constrained expansion. Call costs were separately covered by the Department.



Warren Parker

*Telephone counsellors at work*

In the transitional phase, the BAC was involved in promoting the line, but also provided support to research and monitoring, and contributed to counsellor salaries. JHU-CCP supported, among other things, the new call-centre technology and provided additional technical support. The ongoing collaboration of individuals representing these primary funders ensured sufficient technical understanding and made it possible to explore various avenues to fast-track the funding required to bring about the transition to the centralized call centre.

Prior to the transition, costs of the helpline were approximately US\$350 000 per annum, 45% of which represented the cost of toll-free calls. The cost of the transition was approximately US\$313 000. Currently, the approximate annual cost of maintaining the helpline is US\$800 000, and the cost of toll-free calls is estimated to be US\$60 000. Overall funding is provided by the Department of Health,

with additional support by JHU-CCP/USAID. Bearing in mind that the helpline serves a large population, programme costs may be considerably higher than those of less populous countries, or regionalized programmes that require less staff and lower start-up and operating costs.

### **Recruitment and training of counsellors**

At present, the staff consists of the helpline manager, a call centre manager, a researcher, an AIDS coordinator, a fundraiser, a trainer, three supervisors and three teams of 21 counsellors each<sup>9</sup>. The teams are divided into five front-line counsellors who screen calls and 16 counsellors (who may also help on the front line during call peaks).

The shift from volunteer to full-time, paid counsellors has allowed for the development of a well-defined recruitment and training strategy. Criteria for applicants include:

- previous counselling experience;
- an ability to speak English and three other South African languages;
- at least 12 years of education, with good writing skills;
- previous work experience; and
- age range 22–50.

Counsellors are assessed for their interpersonal skills, and on their problem-solving and decision-making abilities. A positive attitude towards HIV/AIDS issues and an ability to be non-judgemental, respectful of others and compassionate are also important. Counsellors also need to be able to deal with stress.

The training provided to counsellors builds on these basic skills and on any previous counselling experience. New counsellors go through a one-month training course on HIV/AIDS information and counselling that is specific to the helpline systems. This is run internally under the supervision of the training manager. Counsellors also receive technical training in telephone and computer skills.

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<sup>9</sup> The supervisor-to-counsellor ratio of 1:21 is not ideal; 2:21 would be preferable.

Calls include requests for basic information, referrals to local organizations, and on-line counselling support. Counsellors, therefore, need a good understanding of basic AIDS issues, as well as current issues including, for example, new drug therapies. In addition, counsellors must be able to address the AIDS-related myths and rumours that emerge on an ongoing basis.

After the first, intensive month, counsellor training remains an ongoing process, with each counsellor having at least eight hours of formal training every three weeks. This includes further counselling skills, AIDS information updates and technical skills, such as ensuring that data are correctly captured on the system. This training may be as a group or on an individual basis.

On a daily basis, counsellors are mentored and also go through debriefing and stress-relief sessions. Call centre supervisors also identify individual counsellor needs and provide support such as specialized training, 'live buddying' (whereby the supervisor monitors, and assists with, a call) and mock calls.

Helpline resources include a training manual, which is expanded on an ongoing basis, and resources such as books and videos.



**South African AIDS Helpline counsellor answering a call**

Warren Parker

### **Promotion of the helpline**

In the early years, the helpline's rather limited promotion was through print and billboard advertising, supported from time to time by Department of Health booklets and posters bearing the helpline number. During 1997/1998, the helpline was promoted largely through radio advertising as part of the BAC.

In 1999/2000, advertising was expanded to include print (mainly magazines), and outdoor (billboards) and mobile media (trains, buses and taxis). The use of print materials enhanced the impact of the radio advertisements that provided information on the helpline services. Having the helpline number available on print materials contributed to a person's ability to recall/find the number after hearing it briefly on the air.

### **Counsellor profile**

Dikeledi (25) is a psychology graduate who speaks six South African languages. Her initial voluntary work on the helpline as part of her student fieldwork has led to a permanent counselling position. Most counsellors have a natural affinity for this type of work and Dikeledi is no exception. "I realized that in my daily life I was often reconciling the problems of friends and acquaintances. People came to me and told me their problems, and even if I just listened it helped them," she said.

Working on the helpline provides an opportunity to make an important contribution to the lives of others. "I enjoy being there for people who need me most, and it is quite often challenging. For example, a while ago, a man called to say that he was HIV-positive and he wanted to commit suicide. He explained that he was a well-known soccer player, but that he had no one to confide in and lean on, and his family was too far away. He had spoken to his coach, but he was not sympathetic. I was able to help him change his mind about suicide and make him think about his life differently."

One frustration for all counsellors is hoax calls, which usually include abuse. "I have my own strategy for dealing with hoax calls," said Dikeledi. "When there is a hoax caller, I don't let it affect me. I tell myself that I am here for those who need me, and I keep myself ready for the genuine callers." The challenges of counselling also contribute to personal development. "I thought I was strong, but when speaking to others you often realize your own weaknesses. You have to deal with your own weak points, and this has made me a better person."

In a related activity, the BAC established an AIDS Action Office that developed and distributed a wide range of support materials including leaflets, stickers, posters, HIV/AIDS guidelines and utility items such as caps and T-shirts, all of which were branded with the AIDS helpline number. Dedicated posters were also developed for the helpline. During 1999–2000, over 25 million small media items carrying the helpline number were disseminated.

Awareness of the line extends throughout the country, and calls are recorded from both urban and rural areas. A recent Department of Health survey of HIV/AIDS awareness among commuters using public transport<sup>10</sup> indicated that there is high penetration of the notion that a helpline service could be contacted for HIV/AIDS information. Seventy-five per cent of respondents indicated that they knew of such a service. Of those who knew, 56% mentioned the national toll-free AIDS helpline, and 11% indicated that they had made use of a helpline service (ranging from 3% to 21% between sites). One per cent had discussed HIV/AIDS with a helpline counsellor within the past month.



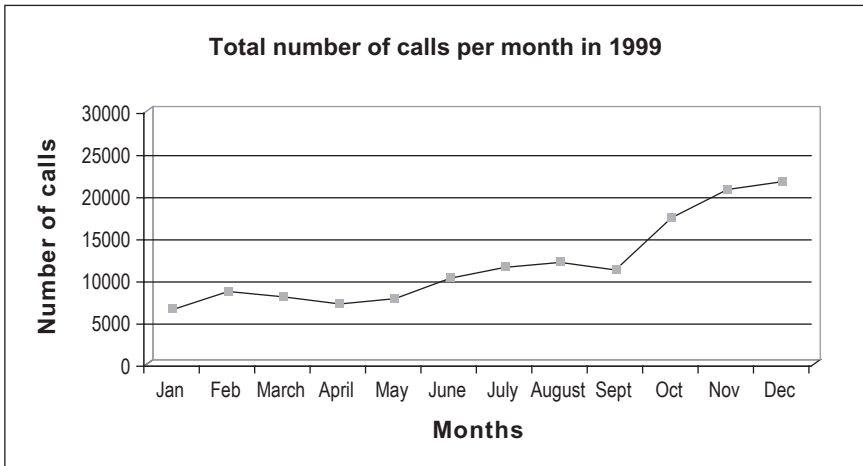
**A poster from the Beyond Awareness Campaign**

By and large, the general availability of the helpline number on leaflets and posters has helped to maintain call rates without additional promotion. Additional promotion increases call rates, and there was a direct correlation between the placement of advertisements and the number of calls to the hotline.

The graph above shows how a radio advertising campaign, initiated in September 1999, contributed to increases in calls logged. At that time, this was the only organization involved in promoting the helpline and there were no other simultaneous promotional activities to account for the jump in calls.

An analysis of sources of the helpline number in August 2000 showed that pamphlets (30%) and posters (8%) were important media.

<sup>10</sup> Warren Parker, Salome Oyosi, Kevin Kelly and Susan Fox, *On the move: The response of public transport commuters to HIV/AIDS in South Africa*, South Africa Department of Health, January 2002.



### Profiles of callers

A computerized system allows counsellors to gather basic information about callers during each call. Data are collated monthly. All calls to the helpline are anonymous and counsellors do not disclose their names to callers.

Data gathered during the last quarter of 2000 have been used to identify the following trends:

*Age:* The majority of callers (45%) are between 15 and 19, followed by the 20–29-year-old age group (accounting for 38%).

*Gender:* While the majority of callers are men (60%), significant numbers of women also call. Reasons for these proportions need to be investigated further, but it is likely that a contributing factor to the higher level of male callers is that proportionally higher numbers of men have access to telephones in the workplace.

*Language:* Each of South Africa's 11 official languages is, on the whole, confined to specific geographical regions. However, because the Gauteng Province, home to the centralized call centre, includes people from all over the country, it is possible to recruit counsellors who speak one or more official languages so the service is truly multilingual. Callers to the helpline are referred to counsellors, based on language preferences. The most common languages spoken by helpline callers are English (29%), isiZulu (19%) and isiXhosa (18%).

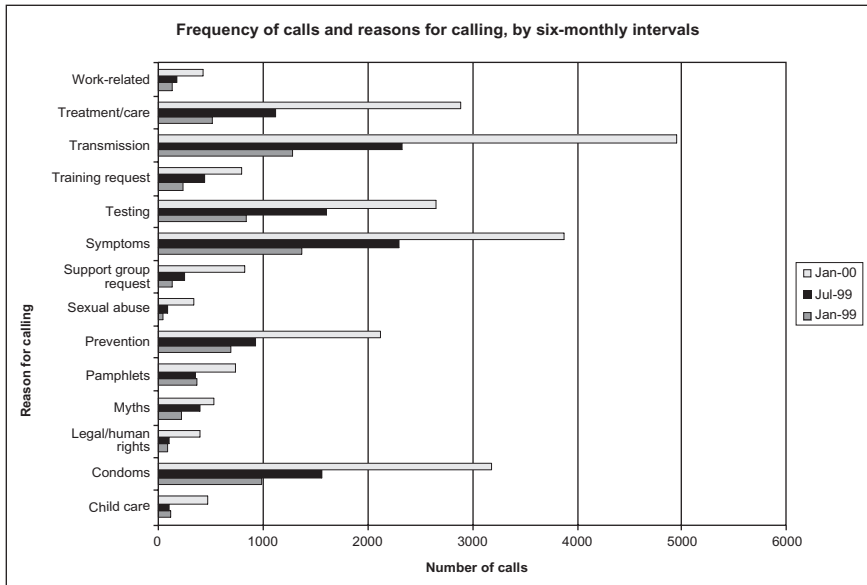
*Geographic distribution:* People call the helpline from all of South Africa's nine provinces. However, some provinces have higher call rates relative to their populations. Factors contributing to higher provincial call rates include regional promotion of the helpline, telephone accessibility, general awareness of HIV and knowledge of HIV status.

### Reasons for calling the helpline

The helpline service provides basic information as well as counselling and referrals. Approximately one-third of calls are counselling calls lasting more than five minutes and approximately two-thirds of callers are referred to services in their area. Three-quarters (77%) of callers are first-time callers.

The graph below details the reasons for calls made during three different time periods prior to the switch to call-centre technology. While the primary concerns are HIV/AIDS transmission, symptoms and other basic information about the virus, callers also ask about condoms, other STIs and HIV testing.

Callers are referred to local services if they require resources (such as condoms), face-to-face counselling and/or HIV testing.



## Challenges

### Failed and hoax calls

A core challenge in delivering a large-scale helpline service is that of ensuring that callers get through and speak to a counsellor. During the transition phase of the helpline (October to December 2000), over 160 000 calls were received each month but, due to staffing constraints, only 60% to 70% were answered, with unanswered calls being considered failed calls. An objective of the call centre is to answer at least 90% of incoming calls.

Only calls lasting more than one minute are logged. Typically, total incoming calls are four-to-six times the number of logged calls. Since 1998, when 70 000 calls were logged per year, the number of logged calls has increased steadily—to 150 000 in 1999 and approximately 220 000 in 2000. Call rates are expected to increase considerably within the budget and framework of the 2001/02 contract, which allows for a full complement of counsellors and support staff.

Several factors affect whether an answered call is classified as a failed or unsuccessful call. For example, a failed call occurs when the caller hangs up, says nothing or if the call is particularly short. While it is difficult to determine why these failures occur, it is possible that some callers are too shy to speak or have different expectations of the counsellor: they might wish to speak to someone of the opposite gender or someone who speaks a different language.

In addition to failed calls, a significant number of calls are considered 'hoax' calls. In this case, callers maliciously abuse the service and/or counsellors. Currently, the ratio of failed/hoax calls to logged calls is three to one—approximately 75% of calls fall into the 'hoax call' category.

Failed and hoax calls have long been part of the South African AIDS helpline and are also a problem of other helpline services in the country. The problem does, however, tend to have affected toll-free services more severely since prank and malicious callers do not have to pay for the calls themselves. Hoax calls incur telephone charges, waste counsellors' time, and frustrate and demotivate counsellors. Counsellors express frustration in dealing with these kinds of calls: *"The only thing that spoils our day is hoax calls"*; *"My stress comes from answering hoax calls"*; and *"Dealing with pranksters wastes valuable time"*.

The failed/hoax call issue can only be dealt with through sustained monitoring, but a number of strategies have been suggested. For example:

- **Classifying failed/hoax calls** to distinguish whether the caller hangs up, is silent, laughs, or is abusive could provide data for developing coping strategies and standardized responses. For example, a standardized response encouraging dialogue could be developed for silent callers; a different response might be used to discourage children's prank calls. Analysis of failed/hoax calls could also, for example, make possible either national or geographically targeted campaigns to promote caller responsibility.
- **Caller Line Identity (CLI)** systems are available through the South African telecommunications system. Recording telephone numbers associated with failed/hoax calls would allow for further analysis, especially with regard to repeated failed/hoax calls<sup>11</sup>. It may be necessary to block calls from certain numbers associated with high volumes of abuse. This would have to be managed in a confidential manner that would not compromise the identity of legitimate callers.
- **Converting to a paid service** might discourage callers unwilling or unable to pay to make a hoax call. However, it would reduce access for poorer individuals and those who require more lengthy telephone counselling. Given the considerable investment that has been made in promoting the toll-free service and the specific helpline number, this approach is not recommended.

## Lessons learned

### A centralized service

The investment made to develop a centralized service has contributed considerably to overall service quality. Using this technology, monitoring calls has become much easier. In addition, centralization allows for counsellor training, development of a referral database, failed/hoax call management and counsellor debriefing to be conducted consistently, thoughtfully and with better planning. Over and above this, the centralized approach to technology and management is considerably more efficient than decentralized approaches. It also facilitates a broad range of data collection.

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<sup>11</sup> Analysis by geographic location of callers, or proportions of workplace, private and payphone calls would provide important insights.

### **Monitoring, evaluation and quality of service**

With a full staff complement and using the best technology available, the AIDS helpline represents a vital and cost-effective resource in the response to HIV/AIDS. However, such a resource is only cost-effective if it meets a range of quality-related objectives and if it addresses emerging challenges insightfully and appropriately.

At a minimum, the following should be included in quantitative monitoring of the line:

- **Call totals:** including calls that were unsuccessful because of a busy signal; the number of incoming calls; the number of calls answered; the number of calls lasting over one minute.
- **Caller statistics:** including age, gender, language, geographic location and how the caller knew the helpline number.
- **Call content:** including whether the call was informational, counselling or referral; first-time caller; reasons for calling.

Additionally, qualitative monitoring is important and should include analysis of the content and problems associated with failed/hoax calls; consistency of counsellor responses; ability to respond immediately to questions about emerging issues (e.g., new treatment options); counsellor perspectives; and support to, and debriefing of, counsellors.

Understanding trends in caller questions is useful in the development of communication campaigns, and it is important to provide communication managers with information on call trends on a regular basis.

Quality-of-service criteria can include: answering at least 90% of incoming calls; answering within three rings; transferring calls placed on hold within 15 seconds; ensuring callers can receive information in the official language of their choice; standardized greetings and responses to common questions; ensuring time efficiency in responding to callers; ensuring referrals to appropriate services; and ensuring that hoax/failed calls are rapidly dealt with.

Part of maintaining a high-quality service also involves ensuring that the referral database is carefully researched and maintained. Developing an effective referral system is a complex and ongoing research activity. The Department of Health regularly updates the national directory of AIDS service organizations, including government agencies, but the quality

of any service in South Africa can vary depending on location, staffing, funding resources, etc.

### **Counsellor debriefing and support**

Any form of information provision and counselling in the area of HIV/AIDS is complex and stressful and, thus, impacts on the psychosocial well-being of counsellors. The anonymous environment of helpline counselling poses special challenges, especially in the case of hoax calls whereby counsellors are subject to abuse, but also in HIV/AIDS counselling where important life-choices may be addressed. A system has been introduced whereby counsellors are regularly debriefed and access to additional counselling is offered.

The helpline staff also includes HIV-infected individuals, and careful attention has been paid to special HIV-related needs in the workplace, with consideration also given to medical and other benefits.

The South African AIDS helpline represents an important and cost-effective activity that has a long history of development. It has taken advantage of modern telecommunications technology to develop a sophisticated centralized call-centre model that works towards the provision of a high-quality service. Many lessons can be learned from the development of this service, both in the technical capacity of the service and in the content of dialogue between counsellors and anonymous callers. Also important is

### **Counsellor profile**

Nathaniel (22) worked as a call centre operator for commercial organizations before joining the AIDS helpline. Over the years, he had seen the need for people to know more about HIV/AIDS, and friends and family members often confided in him. "I wanted to find out more about how to help people," he said. "Of course, 'pranksters' make it hard for us to cope, but I feel that I am empowering callers, and it's likely that they will tell others about their experiences on the line."

Nathaniel has seen the benefits of the changes in the helpline system. "Previously, we worked in different branches of Life Line," he said. "Now we are all together in the same building. We are much better able to deal with problems, and to offer callers their choice of language."

Counselling helps people have better insights into their problems. "One call I remember was when a woman called to say that she was HIV-positive, but had been faithful to her husband. Her husband didn't tell her he was positive, and she had difficulty dealing with the situation. During the call, we were able to shift from these emotions to focus on the importance of living positively with HIV."

Working on the helpline has been a learning experience for Nathaniel. "I have learned other languages and been for further training, and I have a better understanding of how organizations work," he said.

an understanding of the need for careful management and supervision, as well as of the need for debriefing and other support for counsellors.

The cornerstone of effective service delivery has been the integration of monitoring and evaluation activities that provide regular and important insights to guide future strategies and planning. There is also considerable potential for research to inform parallel activities, such as HIV/AIDS communications. For example, an analysis of caller concerns in the area of voluntary counselling and testing might guide both service delivery and communication promoting the services. Similarly, myths and misconceptions could be identified through calls to the helpline and dealt with strategically through a mass communication campaign.

Given the general availability of telephones throughout South Africa, the helpline provides a countrywide service that is accessible from both rural and urban environments. The service provides unique benefits to callers through anonymous information and counselling delivery. In the case of referrals, however, it depends on the relative availability and sophistication of support systems, thus requiring a carefully researched referral database.

High awareness of the helpline is a product of several years of specific mass media promotion of the line. Additionally, promotional support has been provided by the widespread availability of leaflets and posters, which have ensured that the helpline number is well known and accessible throughout the country.

## Contact information

**Helpline number: 0800-0123-22**

Further information on the helpline, including contact information, is available at [www.aidshelpline.org.za](http://www.aidshelpline.org.za)

The author of this report, Warren Parker, can be contacted at [cadrejhb@cadre.org.za](mailto:cadrejhb@cadre.org.za). Tel: +27 11 339 2611. Fax: +27 11 339 2615.

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# The National AIDS Hotline of Trinidad and Tobago

## Trinidad and Tobago

Surface area (square km)	5130
Total population	1.3 million
Urban population	73.6%
GDP per capita (PPP* US\$)	8176
Life expectancy at birth (years)	74.1
Infant mortality rate (per 1000 live births)	17
Adult literacy rate (>15 years)	93.5%
Adult HIV/AIDS prevalence (15–49 years)	1.05%
Adults and children living with HIV/AIDS	7800
Telephones (mainline and cellular, per 1000 people)	246
Internet hosts (per 1000 people, year 2000)	7.7

\* Purchasing power parity

Estimated figures from 1999, where nothing else is indicated.

Sources: *Human development report 2001*, UNDP.

*Report on the global HIV/AIDS epidemic, June 2000*, UNAIDS.

*World development report 2000/2001*, World Bank.



## **HIV/AIDS in Trinidad and Tobago**

**T**rinidad and Tobago is experiencing acceleration in its HIV/AIDS epidemic, particularly in the infection rate of women. The government has recognized HIV/AIDS as a national development priority and has made a significant increase in the national budget for responding to the epidemic.

Though HIV/AIDS was initially predominantly transmitted by men who have sex with men, it now affects the general population.

At the end of 1999, there were an estimated 7800 adults and children (aged 0 to 15) living with HIV/AIDS in Trinidad and Tobago, and 530 deaths were attributed to AIDS. The number of children in the country in 1999 who had lost their mother or both parents to AIDS was estimated to be 685. The current HIV infection rate in Trinidad and Tobago is 1.05%.

In Trinidad, the first cases of AIDS were diagnosed in 1983 in eight homosexual and bisexual men, six of whom died during the course of that year. In 1985, the appearance of cases among women and children signaled that the disease was spreading heterosexually. From 1983 to 1990, the male-to-female ratio changed from 8:0 to 3:1. HIV prevalence among antenatal women in Trinidad and Tobago increased from no evidence of HIV infection in 1988 to 1% of antenatal women tested in 1996. In 1988, 13% of sex workers tested were HIV-positive, but there is no further information on this population group. Between 1994 and 1996, median HIV prevalence among STI clinic patients tested in Port-of-Spain and San Fernando ranged from 6% to 9%.

In a large survey of men and women in their teens and early twenties in Trinidad and Tobago, fewer than 20% of the sexually active respondents said they always used condoms, and two-thirds did not use condoms at all. A mixing of ages, which has contributed to pushing the HIV rates among young African women to such high levels, is common in this population too: while most young men had sex with women of their age or younger, over 28% of young girls said they had sex with older men. As a result, HIV rates are five times higher among girls than boys aged 15–19 in Trinidad and Tobago and, at one surveillance centre for pregnant women in Jamaica, the prevalence rate among girls in their late teens was almost twice that of older women.

In 1987, a Special Programme of AIDS and Information Exchange Centre was established at the Caribbean Epidemiology Centre (CAREC), with

funding from the World Health Organization (WHO). The Centre provided governments in the region with guidance and technical support.

The Ministry of Health (MoH) of the Government of Trinidad and Tobago established its National AIDS Committee by an act of Parliament in 1987, and a National AIDS Coordinator was appointed. Several sub-committees were established, including one for Education and Training.

## **A brief history of the National AIDS Hotline**

The Education and Training Subcommittee was given the mandate to establish, among other things, a hotline service staffed by volunteers recruited from the population. Thus, the Hotline's genesis was via the Ministry of Health and was one of the earliest services provided through the National AIDS Programme<sup>12</sup>. Its structure was to be simple—a quasi-NGO with a management committee and a team of screened, trained volunteers that would operate under the general umbrella of the National AIDS Programme.

The first steps towards making this mandate a reality were taken when a representative of AIDSCOM<sup>13</sup> visited Trinidad and Tobago in 1988 to identify areas in which his organization could provide technical support to the government through the National AIDS Programme. AIDSCOM offered the Ministry of Health funding and technical support for an AIDS hotline. It was agreed that CAREC would be the hotline's facilitating agency and a clinical social worker was appointed to be volunteer coordinator.

The next stage was attendance at a training session in Washington, DC, by a five-member delegation. The intense one-week AIDS/STDs Hotline Development Workshop in the autumn of 1988 exposed the participants to a number of strategic exercises focused on developing an administrative structure and guidelines that would reflect Caribbean social/cultural norms as applied to sex, sexuality and religion. The group visited an AIDS hotline service in Baltimore, Maryland, that was assessed as a potential model because its operational proportions were similar to those needed to serve the population of Trinidad and Tobago. Its selling points were its low budget, and its simple structure and operating processes/procedures. As a result of the workshop, a model was developed for establishing hotlines in the Caribbean region.

<sup>12</sup> From its outset, Aidsline has had the full support of the Ministry of Health and has continued to seek its support whenever appropriate. Having an ongoing professional working relationship with the MoH can be an important asset for any AIDS hotline.

<sup>13</sup> AIDSCOM is a sub-agency of the Washington, DC Academy for Educational Development.

While the workshop was under way in the United States of America, CAREC (in Trinidad) sponsored a series of advertisements in daily local newspapers for individuals interested in volunteering as listeners on the National AIDS Hotline. The Hotline Advisory and Management Committee was formalized, and a subcommittee from the National AIDS Programme was formed to lay the foundation for the first training programme. The first group of volunteers was screened and interviewed by CAREC, and 26 trainees were selected. They represented institutions, agencies and other community groups whose service policies were, to some extent, aligned with those of the hotline.

## **Major elements of the project**

Aidslines, the National AIDS Hotline of Trinidad and Tobago, was formally launched in December 1988. The Ministry of Health provided resource personnel, space for training and an office (including utilities), and continues to do so. CAREC provided technical support personnel and some equipment, facilitated the hiring of an office administrator, and arranged funding for the salary and other start-up expenses through AIDSCOM. The AIDSCOM support included installation of three telephone lines and covering the first six months' phone bills; this was extended to 30 months' coverage after the six-month evaluation.

The hotline currently receives approximately 2000 calls annually on two telephone lines that are staffed from 8am to 8pm, Monday through Saturday. There is one full-time paid employee and a pool of about 40 active volunteers.

Aidslines's target audience is the population at large, but especially the most vulnerable age groups and infected and affected individuals, in accordance with its mission statement: "The National AIDS Hotline of Trinidad and Tobago is in the business of providing credible and confidential information, listening/counselling and referral services that reflect the needs and characteristics of users on matters relating to HIV/AIDS/STIs."

The hotline is informed by its core values: confidentiality, compassion, non-judgemental understanding and a commitment to provide up-to-date, accurate information. It fulfils the following roles and functions:

- It offers a highly confidential, non-judgemental, compassionate and anonymous service to those individuals with anxieties about HIV infection and AIDS.

- It decreases the incidence of HIV transmission in Trinidad and Tobago by providing a listening, referral and educational service.
- It encourages the increase of community participation in HIV/AIDS awareness/prevention/education.
- It offers needed referrals.
- It advances the national planning efforts in HIV/AIDS prevention and control by preparing monthly reports based on analysis of data collected on the hotline. These reports are disseminated to AIDS networks and committees and to the National AIDS Coordinator.

Recently, the role of the hotline for 2000–2005 has been redefined to focus more on providing counselling in addition to ‘listening’, providing information and referrals. The hotline’s role was thus expanded to include:

- HIV/AIDS information and counselling by trained personnel.
- Educating and informing the general public on current issues related to prevention, care and support through supportive media channels and other avenues.

The major elements of the framework developed by the Trinidadian participants at the Washington, DC workshop were generally approved for implementation. Some adjustments were made to reflect local cultural and social customs—such as, for example, the strongly Catholic orientation of the country, with limited resources and a limited support system for which many public health needs must compete. It was felt that the most effective approach to founding a sustainable service would be to limit the number of paid administrators and concentrate on building a strong volunteer base.

This base would also make the hotline as broadly inclusive as possible, bringing to it representatives from many walks of life who would be able to take their HIV/AIDS knowledge ‘home’ and present the issues knowledgeably to their Scout troops, in their classrooms, at club meetings, etc.

AIDSCOM evaluated the hotline after the first six months of operation and, in 1994, the WHO/PAHO<sup>14</sup> Global Programme on AIDS did a quantitative analysis of existing hotline data. Recommendations to upgrade the skills and information base of staff and volunteers were implemented

<sup>14</sup> Pan American Health Organization

with the support of WHO/PAHO. In 1998–1999, the German Technical Corporation (GTZ) provided funds to strengthen the hotline’s capacity through research and evaluation, data entry training, provision of hardware and software, and major adjustments to the data collection instruments.

### **Recruiting volunteers**

The hotline’s driving force is its team of committed volunteers who, especially when it first began, risked ridicule in order to serve those who were suffering in pain and/or isolation. While many people were grateful to finally have a safe place to call for information and support, others speculated aloud about the listeners’ HIV status or branded them as “sinners” who were encouraging “the wrongdoings of those kinds of people”.

Each new group of listeners is asked to complete an application form, submit a résumé and have a face-to-face interview. The selection criteria are: willingness to participate, compassion, the ability to be non-judgemental and open to new information, and being a good listener with a courteous telephone manner. The volunteers are from all walks of life and have varied occupations, religious beliefs and philosophies. They bring their individual uniqueness and skills to Aidsline and have kept the service afloat.

There are currently 120 registered volunteers, of whom 33% are active. Among current volunteers, the age range is from 22 to 70, and the older volunteers bring a valuable, balanced perspective. On average, a volunteer gives one-to-two years’ service after completing training. Most are able to give at least two-to-three hours per week (some more) and, because of their employment and family responsibilities, they are generally scheduled to staff the evening shifts and/or Saturdays. At present, only three or four volunteers are available for weekday shifts and, when necessary, the paid administrative assistant also covers the phone lines. There was a period of two or three years (when the local economy was particularly bad and few people had time for volunteer activities) when the hotline had no weekday volunteers at all. This problem abated as the economy improved somewhat.

Since its inception, the hotline has logged 321 984 hours contributed by volunteers, including the time given by the management committee. If volunteers were reimbursed at the going rate, it is estimated that the hours they have worked would cost the hotline approximately US\$62 000 annually.

### **Volunteer training**

Supervision of volunteers is the overall responsibility of the Coordinator, with support from the administrative assistant (who is also a trained listener) and the five senior (i.e., most experienced) 'listeners'.

When the hotline first began, volunteer listeners were seen as the way to provide the service and it was felt that 'listening' was the service to be provided. It soon became clear that callers' questions and concerns were growing more complex as the epidemic evolved and that the listeners needed to acquire more knowledge and skills. The training and up-grade modules were enhanced to meet the needs reflected in the hotline's data collection sheets. However, after GTZ's 1999 assessment of the hotline using 'ghost callers'<sup>15</sup>, it became clear that while 'listening' was part of the package, it was also necessary to upgrade the listeners' counselling skills. The terminology was changed from 'listener' to 'lay counsellor'<sup>16</sup> and the training began to put more emphasis on counselling skills.

In each session, approximately 25 new volunteers, selected from pools of varying sizes, receive training; 46 applicants were screened for the most recent training session. New volunteers receive 40 hours of training (and often a few hours more) at five consecutive Saturday sessions. For the first 160 hours that they work on the hotline, they are regarded as interns in a probationary period and are overseen by a seasoned listener. This training is designed to help volunteers develop the abilities, knowledge, attitudes and skills required of hotline listeners, including sensitivity to the cultural and social innuendoes of the country's varied populations. The components of the training programme include:

- building a base of scientific knowledge on HIV/AIDS/STI, human sexuality and the elements of safer sex;
- psychosocial dynamics of families and illness;
- understanding the elements of living and coping with HIV/AIDS (and other terminal illnesses);
- self-development/enhancement exercises, particularly to build interpersonal listening and communication skills;

<sup>15</sup> GTZ representatives would call the hotline posing as a 'regular' caller and assess the service provided.

<sup>16</sup> The term 'lay counsellor' is used because none of the volunteers is a counsellor by profession or has a related academic degree.

- the principles of the hotline, in particular the guiding principles of confidentiality and non-judgemental respect for callers' privacy;
- the practices of the hotline, e.g., record-keeping and referrals;
- telephone etiquette, handling of crank calls, etc.; and
- introducing and enhancing basic counselling skills using the 'five-stages model' developed by psychologist Carl Rogers.

Twice each year, volunteers receive 10–15 additional hours of training to upgrade their skills. This involves analysis of the data sheets and the issues they highlight, role-play and discussion, etc. All volunteers, whether currently active or not, are invited to these sessions, as the information can be valuable in other venues as well. In addition, informal seminars and updates are part of the line's regular monthly meetings, as is analysis of specific calls and issues. Volunteers also have the opportunity to attend conferences, workshops at the national level and other relevant events. In essence, volunteers' education is ongoing in an effort to address the rapidly emerging issues associated with HIV.

### **Profile of a volunteer listener**

"I volunteered for the hotline service when it first started, after I saw an advertisement in the newspaper. I had heard about AIDS on the news—that it was spread by sex, by having multiple partners—and that scared me because I was divorced and it related to my lifestyle. And I had seen a foreign programme on AIDS that ended by stating that if you knew of any project in your community, get involved. I was used to volunteering in other agencies, and I felt that I could play a role.

"I have had many memorable experiences on the line. One caller's brother, who lived abroad, had confided in her that he had full-blown AIDS and asked her not to tell their parents. She had no one to talk to and called frequently, saying the hotline was her only support system. I was so glad I was there. I was especially touched by a caller who learned that her boyfriend was bisexual only when he died of AIDS. His parents had kept the information from her. I'll never forget that woman's voice and, later, when my 11-year-old son died tragically, I realized what she must have been feeling. The other listeners and the Coordinator were very supportive and helped me through the bereavement process.

"I have witnessed changes over the years. Callers are now more open, more trusting of the line. Younger people are volunteering. The big change is in the data forms, which are more in-depth. The state of the economy is bad, and I believe that contributes to some volunteers' not being able to stay, but they are still committed to the organization.

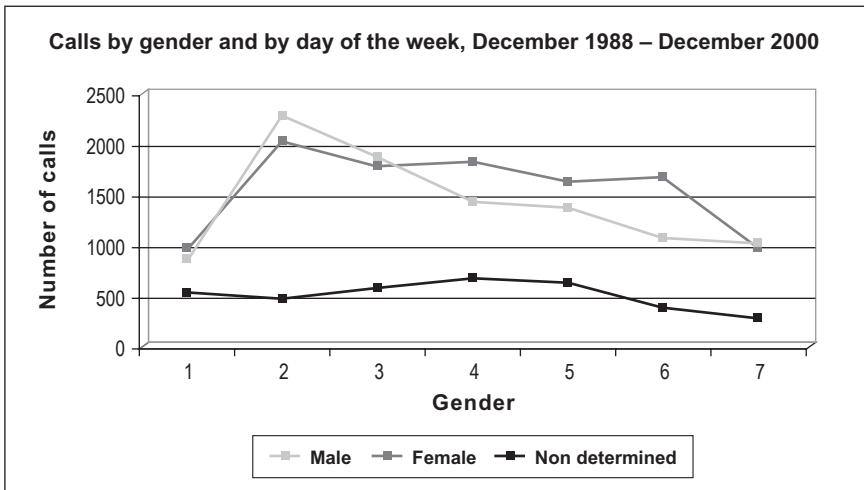
"I volunteer because I need and want to be here. Committed volunteers are the strength of the hotline and struggle along with it when funds are low. Lack of funds is the line's weakness, but somehow we always manage to pull through. Still, people do not seem to understand just how serious the HIV/AIDS situation is in Trinidad and Tobago."

**The callers**

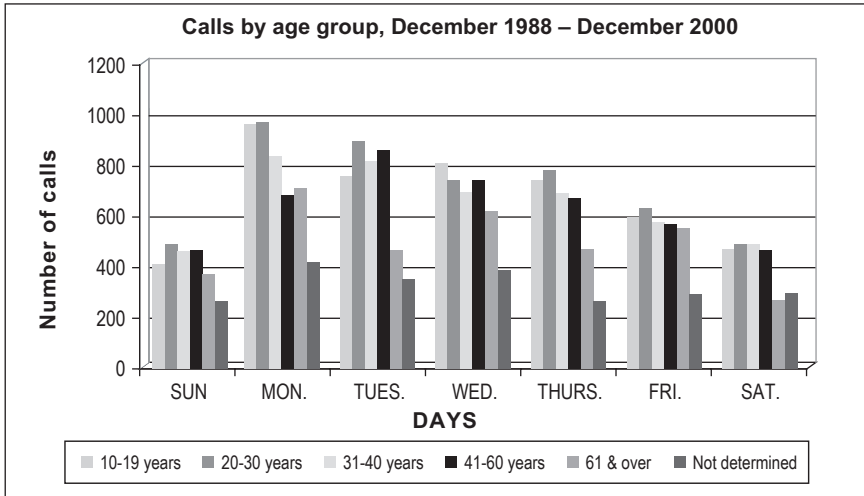
Callers' concerns have changed over the years, moving from an early focus on the need for basic HIV/AIDS information (e.g., symptoms, transmission, testing sites) to issues reflecting the growing impact of the virus on families, individuals, social groups, workplaces, etc. (e.g., sexuality, prevention of infection within stable relationships, grief and loss). Consequently, resource manuals have been updated over the years to make both the information presented and the referrals to agencies, professionals or institutions more appropriate.

Aidline has kept manual data sheets on callers since the beginning. These have been upgraded over time to include more information, including behavioural aspects and service needs. The data began to be computerized some years ago, but the hardware and software were unreliable and some statistics became skewed. The administrative assistant, with the support of volunteers with computer skills, is now transferring the manually collected data to new computers provided by GTZ in 2000, and should finish in early 2002.

The data indicate that various social strata, levels of education and employment, and sexual preferences are represented among the callers. The ratio of male-to-female callers is relatively close, especially at present, as shown in the chart 'Calls by gender'.



While the majority of callers are in the age groups most affected by the epidemic, as the 'Age group' chart indicates, the calls are relatively evenly distributed among age groups. Note also that more calls are received on Monday than on any other day of the week, and the number of calls diminishes daily, flattening out at the weekend.



Revised statistics on the number of repeat callers are available for the years 1988 through 1997. Overall, 17% of callers say they have called before, with the number of repeat callers having been highest in the first three years of operation, then levelling off.

By the end of 2000, the hotline had recorded a total of 24 554 calls. The great majority of calls result in an interaction between the caller and listener. When the hotline first began, there were many 'silent' callers who could not work up the courage to speak. The listeners try to encourage such callers to talk and, if unsuccessful, urge them to call back when they are feeling bolder. Many callers have acknowledged that they called several times before finally speaking. In recent years, as people have come to address the issues of HIV/AIDS more openly, there are fewer silent callers and an increase in calls from individuals asking how they might help a friend, neighbour or relative in need of information or support.

Callers' questions generally fall into the four categories described in the 'Reasons for calling' sidebar. Calls may also fall outside these catego-

ries, of course, with some of the most frequent being: complaints about general medical care and queries about medical symptoms that are not HIV-related; and questions about the correct way to use a condom and about possible substitutes for condoms.

### Reasons for calling the hotline

These fall into four distinct but interrelated categories:

The needs of persons living with HIV/AIDS, for example:

- Looking for a compassionate ear, “just wanting to talk”.
- I am pregnant; will my baby be born HIV-positive? Is there any medication/treatment to prevent my baby from contracting HIV?
- Disclosure issues: “Who do I tell? I have already been betrayed.”
- “I had to be tested for a position; I am positive. What can I tell my parents? They invested in my education.”
- Seeking information about herbal remedies and nutrition.

General information-gathering, for example:

- Where are the testing sites? What does the procedure involve?
- What is, and where do I get, pre/post-test counselling?
- I am entering a new relationship, and considering getting tested.
- Request for information based on callers’ descriptions of lumps, rashes, etc. on genitals.
- What is the relationship between drug use and HIV?
- What is the government doing?
- General information on HIV/AIDS/STIs—e.g., modes of transmission, length of incubation period, signs and symptoms.

Questions centred on human rights/ethical/legal issues, such as:

- Denial of access to/loss of employment or housing.
- Poor access to health care and poor quality of care in hospitals.
- Mandatory testing for employment and insurance.
- What laws are in place regarding wilful spread of the virus and discrimination?
- Are there recourses for victims of incest and domestic violence?
- How private are the test results?

Questions about unhealthy/abusive relationships and related social concerns:

- Rape/incest/domestic violence.
- Unsafe sexual behaviour/practices putting a relationship at risk.
- Unprotected sex with ‘old flames’.

The line also gets, all too commonly, calls asking if it is a 900-number sex service. These calls are to be differentiated from the very infrequent calls in which male callers make personal, sexually-related comments to female listeners. In addition to these rare abusive calls, some prank calls also come in, especially during the holidays when children can be

heard giggling on the line. In addition, very few callers preach to the listeners about the morality of offering a service to “those people”. (The counsellors’ response is simply to thank them for the conversation when they have finished having their say.) In general, however, prank or abusive calls have been, and remain, rare—perhaps one or two each month. This might be partly attributed to Trinidad and Tobago’s culture, which stresses politeness on the telephone.

## **Challenges**

### **Increasing the number of calls from outlying areas**

Sorted by point of origin, it appears that the greatest number of calls generally comes from urban St George, and that more calls come from areas with higher incidences of HIV/AIDS as reported by the Trinidad and Tobago Public Health Laboratories than from rural, low-incidence locations. However, there is no way to verify the location from which a call is placed to the hotline, nor whether the caller resides/works in that area.

Early on, Aidsline investigated offering a toll-free 800 number but, at that time, the technology was not readily available. In 2000, an 800 line was again considered as a way to encourage callers in outlying areas, and it was decided to seek funding for that project.

Two strategies have been proposed specifically to increase calls from Tobago: an 800 line and/or a call-forwarding scheme that would transfer a call made to a local Tobago number over to the hotline in Trinidad. Neither has been implemented, and Tobago is currently seeking to set up its own hotline services.

### **Retaining active volunteers**

Another major challenge and ongoing source of concern is that of keeping volunteers as active hotline participants. Most of those who are unable to continue as active listeners remain committed to the project, and there is a high level of participation in celebrations and fundraising projects. Nevertheless, losing active volunteers in whom many hours of training have been invested is a problem. The difficult economic situation could be a contributing factor to high turnover, and although the employment situation is not as bad as it was a few years ago, the cost of living continues to rise. Volunteers have always travelled to the hotline at their own expense, and as their family needs change, so do their budgets. It might be useful to investigate introducing stipends as one approach to this problem.

At one time, call-forwarding technology was considered a possible approach. Calls were forwarded to the listeners' homes or other locations where they might work more conveniently on the Aidsline. However, the lack of privacy was a problem, and the practice could not be continued. The idea had merits, however, and will be revisited in the near future.

### **Promoting the hotline**

Between 1988 and 1990, AIDSCOM provided significant support to promote the hotline service. Two billboards (a major source of new calls), brochures, bus cards and pink 'safe sex' cards all advertised the hotline. The descriptive 'safe sex' cards caused the hotline to be accused of contributing "to the detriment of minors". During that same time period, the hotline also had access to free radio time at night for its own programme, *The National AIDS Hotline Presents*, produced by the Aidsline coordinator in collaboration with the station. The programme aired for about four months and was well received.

At present, however, the hotline has little access to the electronic media, for there have been significant changes in this sector. A few years ago, the media took a strong business focus, meaning that airtime or print space had to be purchased by the organization rather than being provided free of charge. Free 'charity filler/community announcement' space is still available in the print media. The *Express* newspaper/TV 6 Group was the first to provide the hotline with free space daily to advertise the service, and it has continued to do so. Some years after the *Express*, other print media began offering the hotline a similar service. Occasionally, the hotline gets some radio/television sponsorship, but generally access to the electronic media is now primarily through the Information Division of the Office of the Prime Minister. The division provides access to its technology to produce tapes that are aired in the time slots that radio and television stations must provide to the government.

### **Remaining sustainable**

Ten major donor agencies and organizations have helped the Aidsline meet its financial and programmatic needs, particularly in the early years. However, the recent decline of international funding sources and the slow uptake of funding by national corporations have, at times, put the service at risk—despite ongoing volunteer fundraising efforts and board members' contributions of accounting, promotional, legal and management advice/services.

Aidline's original budget was US\$11 440 (TT\$70 000), which covered one full-time and two part-time staff members and three telephone lines. Aidline continued with two full-time employees and three telephone lines until three-and-a-half years ago, when the budget had to be revised downwards in the wake of severe cuts in international funding. The current annual budget is approximately US\$7350 (TT\$45 000), which funds one full-time employee and two telephone lines. A third line has also been installed to facilitate access to the Internet.

Funding the hotline remains a chronic problem that has not been adequately addressed. The challenge is increased by the fact that the hotline competes for scarce resources with other NGOs, including other AIDS-specific agencies. Hosting 'fetes' and barbecues is a common fundraising activity among NGOs in Trinidad. The fetes (which feature music as well as food and dancing) are the most profitable, and the volunteers have hosted many. However, producing them requires capital up front, and the hotline no longer has discretionary funds.

The hotline is currently applying for government funds that have been approved to sustain the ongoing services of NGOs. These funds would provide for some of the staff and services the hotline would like to retain.

## **Lessons learned**

The National AIDS Hotline of Trinidad and Tobago was established with great efficiency over a short period of time in 1988 as one of the country's first responses to the HIV/AIDS epidemic. Based on a US model, it was tailored to the more conservative cultural and social realities of Trinidad and Tobago, and it acknowledged the country's economic realities by basing itself strongly on volunteerism. The project cannot currently afford to pay professional telephone counsellors.

Major hotline funders have conducted evaluations over the years and their recommendations have been implemented. This has resulted in an expanded capacity for research and evaluation via increased data collection and an improved, computerized database. It has also upgraded the skills and information bank of its volunteers and staff, and moved their function from 'listening' and providing information to an expanded focus on counselling. This is a transition other hotlines have also decided to make as community needs become clear and the epidemic expands.

Tens of thousands of calls have been taken over the past 13-plus years, providing a vital community service at a fraction of the cost were the service not volunteer-based. The Aidsline would no longer exist if it were not for the volunteers' tenacity, even in the face of their own hardships. It is a measure of the value they, as representatives of many communities and walks of life, place on the service the hotline provides.

It is difficult to judge the effectiveness of such a service. Trinidad and Tobago is a small country and the telephone allows people to present their problems in privacy and receive referrals to needed services. While callers are asked to report back about their experience at a referral agency, most do not. Aidsline hopes eventually to implement bilateral tracking<sup>17</sup>, although it is understood that most people would rather not tell an agency that they had got the referral from Aidsline<sup>18</sup>. None the less, the fact that, on average over the years, one out of every five or six callers calls back, indicates that the hotline service is relevant to, and well accepted by, the community. Callers give the counsellors feedback, indicating that the hotline has carried them through a crisis, given them valuable information, etc.

Despite ongoing funding problems and attendant budget cuts, the hotline has been sustained and continues to provide services that have expanded (e.g., more counselling) to meet the changing needs of callers. Despite the desire to do more, like every agency, the hotline has its limits. Aidsline's limits are defined by the parameters of telephone counselling. If the level of paid staff could regain its former peak, Aidsline would be able to provide a better and more extensive service; nevertheless, the organization has adjusted to the economic reality it faces. The hotline has striven throughout to maintain its effectiveness and relevance, while maintaining the ethical principles upon which it was established: confidentiality, compassion and understanding, and non-judgement.

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<sup>17</sup> An agency would ask clients who had referred them and would report back if the referral came from the hotline.

<sup>18</sup> People referred to HIV testing or services might acknowledge the hotline as their source, but those referred to services not directly related to HIV probably would not.

## **Contact information**

**Hotline numbers: (868) 625-2437, 625-0646**

The National AIDS Hotline of Trinidad and Tobago  
#7 Queen's Park East, Port-of-Spain,  
Trinidad and Tobago

Contact Person: Ms Helena Joseph, Coordinator

Tel: (868) 625-2437

E-mail: [aidsline@tstt.net.tt](mailto:aidsline@tstt.net.tt)

## **References**

Pan American Health Organization (PAHO) (1997) *Health conditions in the Caribbean*, PAHO Scientific Publication #561.

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# The Remedios AIDS Foundation Hotline

## The Philippines

Surface area (square km)	300 000
Total population	74.3 million
Urban population	57.7%
GDP per capita (PPP* US\$)	3805
Life expectancy at birth (years)	69
Infant mortality rate (per 1000 live births)	31
Adult literacy rate (>15 years)	95.1%
Adult HIV/AIDS prevalence (15–49 years)	0.07%
Adults and children living with HIV/AIDS	28 000
Telephones (mainline and cellular, per 1000 people)	77
Internet hosts (per 1000 people, year 2000)	0.4

\* Purchasing power parity

Estimated figures from 1999, where nothing else is indicated.

Sources: *Human development report 2001*, UNDP.

*Report on the global HIV/AIDS epidemic, June 2000*, UNAIDS.

*World development report 2000/2001*, World Bank.



## HIV/AIDS in the Philippines

According to UNAIDS, the estimated number of adults and children with HIV/AIDS in the Philippines at the end of 1999 was 28 000. HIV is largely sexually transmitted, and the adult prevalence rate at this time was 0.07%.

The Philippines remains a low-HIV-prevalence country. The number of HIV/AIDS cases is not expected to increase substantially over the next few years.

The Philippines has been described as having a “low and slow” epidemic curve. According to Michael Tan et al.<sup>19</sup>, several factors account for this. Firstly, population movement is more restricted on the Philippine archipelago than, for example, in mainland South-East Asian countries that share land borders.

Secondly, multisectoral initiatives played a significant role in developing and implementing national AIDS policies. This multisectoral approach greatly increased the chance of success for programmes providing HIV/AIDS prevention information. The Philippines also rejected implementing mandatory testing as a ‘preventive’ measure, and Tan et al. credit this decision with also helping to slow the epidemic.

Thirdly, some socio/cultural elements of Philippine society may also play a role. Sexual conservatism predominates among Filipinos. A 1999 study<sup>20</sup> suggests that 4% of married women and 16% of married men have extra-marital relationships. Another recent study<sup>21</sup> found that, in the preceding 12 months, 87% of men were monogamous. Circumcision of Filipino males is a common practice that may also contribute to low prevalence rates. In addition, Filipinos have a low incidence of injecting drug use.

Finally, an adult literacy rate of 95% has made it easier for information, education and communication interventions to reach the majority of the population.

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<sup>19</sup> See: Tan M, Cheng K, Lamug J (2000) *A matter of time: HIV/AIDS and development in the Philippines*, Health Action Information Network (HAIN), National Economic and Development Authority (NEDA), UNDP; and Tan M et al. (2000) *HIV/AIDS Country Profile: Philippines*. PNAC, Manila.

<sup>20</sup> Raymundo CM, Xenos P, Domingo LJ (eds) (1999) *Adolescent sexuality in the Philippines*. University of the Philippines Office of the Vice Chancellor for Research and Development, Quezon City.

<sup>21</sup> Jimenez PR, Lee RB (2001) *Male sexual risk behavior and HIV/AIDS: A survey in three Philippine cities*. De la Salle University Behavioral Science Department.

Certain populations are at increased risk of HIV infection. There is a high prevalence of STIs among sex workers. Sharing of needles was reported by 77% of injecting drug users (IDUs) and unprotected sex was reported by 92% of men who have sex with men and 96% of IDUs.

The first case of HIV in the Philippines was diagnosed in 1984. In 1987, the National AIDS Registry was established. The Philippine AIDS Prevention and Control Act (groundbreaking legislation that took a rights-based pre-emptive approach to the epidemic, stressing prevention campaigns) was enacted in 1998, and rules and guidelines for its implementation were formulated the following year. The Government's Medium Term Plan III (2000 to 2004) contains basic strategies such as sustained HIV prevention, ongoing research and surveillance, small-scale trials focused on risk reduction and HIV impact management, expanded implementation of effective risk-reduction approaches, and care and support of those infected and affected by HIV/AIDS.

To complement the national response, local and community responses by Philippine NGOs began in the early 1980s and developed a broad range of initiatives for reaching vulnerable populations and communities at risk. Despite the scope of these efforts, Medium Term Plan III recommends that the country's response needs to be scaled up, accelerated and expanded ahead of the spread of HIV infection. The efforts initiated may appear disproportionate in relation to the number of actual cases, but they will take advantage of the window of opportunity that is currently available to control the epidemic.

## **Telecommunications overview**

Telecommunications services in the Philippines are well suited to provide hotline callers with a reliable, affordable and accessible telephone service. Ample home, office and public lines are available nationwide. In July 1993, a government order to improve both urban and rural local exchange services required installation of 300 000–400 000 service lines over a five-year period (1 new rural line for every 10 new urban lines). For the majority of Filipinos, making a public phone call and/or maintaining a telephone or cellular line is affordable.

A three-minute local call on a landline call costs around US\$0.10–0.15 (PhP5) and a long-distance call costs US\$0.10–0.40 (PhP4–20) per minute. A cellular phone call costs about US\$0.20 (PhP8) per minute.

## **A brief history of the Remedios AIDS Foundation**

Remedios AIDS Foundation, Inc. (RAF), a NGO, was founded in 1991 to “provide quality sexual and reproductive health information and direct services to people, with focus on vulnerable individuals and communities affected by the HIV/AIDS pandemic.” RAF has since expanded to address the full range of reproductive health issues. The Academy for Educational Development (part of AUSAID) provided RAF’s initial funding. Today, RAF is supported by both local and international donor agencies. In its mission statement, RAF envisions a society “where all people, regardless of gender, age, sexual orientation, ethnicity, religion or economic status, have access to quality reproductive health care and are able to exercise their sexual and reproductive rights”.

RAF does both networking and advocacy around HIV/AIDS and reproductive health issues, in addition to administering and providing a broad spectrum of reproductive health-related services including:

- The Counselling Programme, which offers four information/counselling venues for the general public: the telephone hotline, face-to-face meetings, an Internet chatroom and a weekly radio call-in show.
- The Training Institute, which provides training for reproductive health counsellors, hotline phone counsellors and peer educators, and also holds workshops and seminars on issues related to its mission, as well as establishing an ‘AIDS in the Workplace’ programme.
- Three clinics: Clinica Remedios, Malate Clinic and Kalusugan@com, all providing the same HIV/AIDS/STI and reproductive health services.
- RAF develops, produces and distributes information, education and communication (IEC) materials, including an NGO directory and manuals/guidebooks on HIV/AIDS/STI and reproductive health and on counselling and care services.
- Youth Zone, an adolescent-friendly, shopping-mall-based centre that provides information and direct clinical services on adolescent reproductive health at Kalusugan@com clinic.
- A community support centre for people living with HIV/AIDS, which offers psychosocial counselling services for individuals,

couples and families, peer support, return-to-work opportunities, art therapies, basic alternative/complementary treatment therapies and funeral/burial assistance.

## **The birth of the hotline project**

Called the Philippine AIDS Hotline when it first started in January 1991, the Remedios AIDS Hotline was one of RAF's pioneer programmes. Its goal is to provide callers with access to accurate, credible and confidential information and counselling services on HIV/AIDS and other reproductive health concerns so that they can make informed decisions affecting their health. The hotline is available to callers from anywhere in the country but, in fact, 90% of calls come from within Manila and the other 10% from nearby provinces. Long-distance phone charges inhibit calls from outside the local calling area. Some provinces, such as Negros, for example, have local hotlines and other agencies have set up referral hotline numbers that do not provide counselling. RAF is the only full-service hotline that has been able to sustain itself.

Initially the hotline operated 14 hours a day (except on holidays), on a single telephone line staffed by three volunteer counsellors who provided basic HIV/AIDS information. It quickly became clear that callers wanted information on STIs as well, and that was provided as of 1992. At first, the hotline received 1–5 calls per day but, from 1996 to the present, it has averaged 20–30 daily calls. The Remedios AIDS Hotline has three telephone lines operating from 10am to 10pm, Monday through Saturday (except on holidays), with three or four volunteer counsellors on duty at all times. It provides information on HIV/AIDS and STIs, general reproductive health issues, gender and sexuality, and also refers callers to other services offered by RAF and its partner agencies.

At first, almost 95% of callers were male. To boost the number of female callers, a Women's AIDS Hotline was established in May 1993 and staffed by female counsellors. The percentage of female callers rose to between 15% and 20% by 1995 when reproductive health issues were formally integrated into the information/counselling/referral scope of the hotline. This was done partly in response to the concerns of female callers and partly in order to encourage more women to call. The number of female callers has generally remained at 15–20%, although it sometimes peaks at 30%. The availability of a confidential, anonymous hotline specifically for them appears to have made Filipino women more comfortable in talking about their reproductive health concerns and, in

turn, the counsellors' skill in discussing those concerns may have attracted more female callers. The women's line is staffed by at least one female counsellor from 10am to 10pm every day but Sunday.

In 1994, use of the hotline service reached its peak as a result of massive print, radio and television HIV/AIDS campaigns conducted by the national government. The hotline was receiving 30–70 completed calls per day, as compared to 20–30 today. Two factors were largely responsible for the decline: Firstly, after 1995, the government budget for the multimedia information, education and communication campaign was cut, so the hotline phone number was no longer constantly in the public eye. Secondly, in 1996–1997, all Philippine telephone numbers were upgraded from six to seven digits, and the new hotline numbers were longer and more difficult to recall. A number of strategies were used to promote the new numbers, but none provided the regular, broad-spectrum exposure enjoyed during the government's awareness campaign. The negative impact of this change is still being felt.

RAF compiles caller profiles and collates them using EPI Information Version 5 software. All counsellors take calls and complete the Hotline Call Report (HCR), which is an important tool of the project. RAF's adaptation of the Whitman Walker call report was introduced in 1992 and tracks the following caller information: demographic profile, concerns expressed, risk exposures/activities, condom use, number of sexual partners, and where the hotline number was obtained. A detailed narrative summary of callers' concerns and counsellors' responses is appended to the HCR. Counsellors may also probe callers for additional information on contraceptive options and usage, STI risk assessment and sexual behavioural patterns. To win their trust, counsellors assure clients of the utmost confidentiality.

The hotline data provide insights that help RAF tailor its services to reach specific clients and population groups in a non-discriminatory, non-stigmatizing fashion. Hotline data on topics such as condom use or exposure to high-risk behavioural practices can fill gaps in RAF's analysis and contribute to the design of programme interventions. For example, for the past 10 years, callers' reported condom use rate has been consistently below 20% and just above 10% for callers who are at increased risk of acquiring HIV. This is despite the fact that access to condoms has improved greatly in the Philippines in recent years. There is a need to put into context callers' reasons for not using condoms, the most common of which are: decreased pleasure/sensitivity; caller knows

partner; and partner looks clean. The static condom use rate may be related to the increase in the number of young people calling the hotline. Initially, youths aged 16–20 comprised 30–40% of callers, but this had increased to 60–70% by 2000. Further studies of the static rate are required in order to clarify this trend.

Hotline data have helped RAF give birth to other innovative projects and venues for counselling:

- Hotline callers often said that they would feel more comfortable being referred to clinical services provided by the same institution that operated the hotline. Founding its three clinics helped RAF complete the circle of its services so that clients can either go to a RAF clinic or to one from the network of referral agencies. If a client stays within the RAF system, it solves a classic problem faced by hotlines: difficulty getting feedback from referring agencies about whether hotline clients actually availed themselves of the services. RAF clinics provide immediate feedback, and referrals coming from the hotline are adequately tracked. About 90% of hotline referrals do present themselves at a clinic. Clinic and hotline confidentiality are preserved at all times and all caller/client record-keeping is in code.
- In 1998, a RAF project to address the needs of youth gave birth to the Youth Zone programme. Data from the hotline indicated that adolescents needed an accessible and acceptable place to go for health information. Youth Zone aims to empower them to make informed decisions on matters relating to their sexual and reproductive health. To promote this, Youth Zone is using information technology as a strategy. Every month, it conducts 300 to 500 chat-room counselling sessions online. Because counselling is online and users of chatlines use pseudonyms, confidentiality is assured. Should referrals need to be made, either the hotline numbers are provided for phone counselling and referral or, if chatline users are far from RAF clinics, they are referred to the nearest hospital clinic. An initial drawback of this programme is the start-up cost and the expense of hiring computer-literate staff, but proposed user-fee mechanisms could make it more viable. It has definitely attracted youth to discuss these issues in a new forum.
- In February 2001, RAF partnered with a famous local clinical psychologist/sex therapist on her weekly two-hour radio programme, 'The Naked Truth with Dr Margarita Holmes'. For a six-

month period, RAF staff provided radio counselling on the air and referrals were made to the hotline for follow-up, as airtime was very limited. This initiative attracted listeners and helped break down the barriers to discussing sensitive matters more openly. It is hoped that this sort of outreach could be expanded, but support is needed from both private institutions and/or donor agencies.

### Demographic profile of hotline callers 1992–2000

	1992	1995	2000
<b>Total number of callers</b>	12 252	20 310	18 487
<b>Average number of calls/day</b>	35	53	30
<b>Most common age range</b>	16–20	16–20	16–20
<b>Caller's sexual orientation</b>	78% heterosexual	73% heterosexual	74% heterosexual
<b>Top three hotline concerns</b>	HIV/AIDS gen. info. HIV transmission HIV testing	HIV/AIDS gen. info. STIs Sexuality	Reproductive health HIV/AIDS STIs
<b>Percentage of callers with sexual risk exposures (both sexes)</b>	Not available	50%	50%
<b>Percentage of condom usage among callers with risk exposures</b>	Not available	10.65%	10.20%

## Major elements of the project

### Hotline staff and volunteers

The RAF hotline project's minimum staffing requirements include one coordinator, an assistant coordinator and a pool of volunteer counsellors. The coordinator oversees day-to-day operations and leads the annual volunteer counsellor-training workshop. Volunteers are recruited during the first trimester of each year by placing announcements in schools, universities and in the newspaper. Applicants must be at least 18 years of age, have good communications skills in both English and Filipino, and demonstrate a commitment to community service. Those who meet these criteria are interviewed on their beliefs/values and given a psychological examination. On average, there are 100 applicants for the counselling workshop each year. Only 20 are selected.

The volunteers are generally college students and young professionals who often study or work in allied fields such as nursing, social work, medical technology, etc.

Volunteers cite a number of reasons for joining the hotline counsellor pool. The counsellor training and ongoing opportunities to attend workshops and conferences provide professional educational opportunities and develop interpersonal communication skills that the volunteers (most of whom are under the age of 25) feel will benefit them in future. When paid positions become available at RAF, volunteers are given priority; and volunteers also feel that having worked at RAF gives them an edge when applying for work outside the Foundation. RAF looks to the pool of volunteer counsellors when it contracts for professional skills, such as technical writing, research work, computer graphics, medical consulting, etc. Hotline volunteers are also provided with a modest honorarium to cover on-duty meal and transportation expenses. Volunteering also provides an expanded social circle and a certain standing in society.



Remedios AIDS Foundation Hotline

*Telephone counsellors at Remedios*



*Remedios leaflet*

### **Profile of a counsellor at Remedios AIDS Foundation**

Grace was 20 years old, a new graduate with a Bachelor of Science in nursing, and looking for a job when she came across Remedios AIDS Foundation, which was looking for volunteer HIV/AIDS counsellors.

“It was not easy, at first. When I was still a neophyte, I always felt my chest pound with agitation when the hotline phones rang. I sometimes had this sense that I might not be able to address the concerns of my counsellees. But with the training and workshops to strengthen our counselling skills, and the never-ending motivation and assurances of my seniors, almost everything became clear.

“Regular counselling practices also helped enhance my skills, and awards and recognition inspired me to continually perform. As I moved forward, my potential was explored and my capacity to do more, beyond counselling, was strengthened.

“One particular hotline case has always stayed in my mind. My counsellee was supposed to have married a few months before he made the call. He had always tried to preserve his fiancée’s virginity, but she had been raped by her supervisor. It was so painful for the caller that he attempted to commit suicide. I could feel his pain. My voice was about to break, but I took a deep breath and comforted him, explaining how important it was to be strong for his fiancée because she needed him in that time of agony of losing dignity and power. He could be a source of strength and courage, but not if he gave up too. I know he was jolted awake. From then on, I received follow-up calls from him, and his fiancée as well, expressing how thankful they were for the changes that that call had made for them.

“I have always believed that effective counsellors should be open to, and accepting of, their own personal experiences. We promote healing of deep wounds, empowerment and other things to help people attain quality of life, but have we given these to ourselves? A strong counselling experience has enriched my personal life as well. I have learned to look at my past not with regret but to learn more about how it has made me a better person.

“As time passed, it became a struggle between having a financially stable job and continuing the counselling service. I am now a HIV/AIDS Caregiver—a position that includes, but obviously goes beyond, being a counsellor, yet both [roles help] enhance the quality of life.”

### **The Hotline Counselling Training Workshop**

RAF has developed an extensive training curriculum and programme for hotline volunteers. Until 1995, this consisted of an 80-hour training programme over two weeks for all 20 new volunteers. Presentations and discussions of information and role-playing were the principal teaching techniques. After the training, participants’ knowledge and skills were assessed on the basis of a comprehensive examination (a score above 75% was required) and a mock telephone-counselling session.

Given the growing budget constraints, this training programme eventually proved too costly and time-consuming and, in 1998, RAF implemented a shorter training that paired each new volunteer with a buddy who provided oversight and mentoring during the volunteer’s initial work on the helpline. Under this Buddy System, 30 hours of training take place over the course of five meetings, each lasting six hours and

having only five or six attendees. Under the 80-hour plan, new topics and information were introduced and discussed during the training sessions. The Buddy System relies on participants' reviewing assigned topics between meetings and coming to meetings prepared to discuss the issues and concerns their assignment raised. Ideally, discussion groups and role-playing dominate these meetings, providing more room to discuss sensitive matters than did the 80-hour system. However, RAF has found that bringing volunteers who have not completed their assigned review up to speed can significantly slow down the training process.

During the initial training and in follow-up workshops, the modules covered at RAF include: basic HIV/AIDS and STI information and counselling; gender-sensitivity training; family planning motivation and counselling skills; handling sensitive issues such as abortion, adolescent sexuality, premarital sex, domestic violence, sexual harassment, substance use and abuse; dealing with youths; and addressing the concerns of persons living with HIV/AIDS, men who have sex with men, sex workers, etc.

Remedios AIDS Foundation Hotline



***Telephone counselling workshop***

In addition to skill-building, a hotline project needs to provide frequent updates to ensure that the messages and information being provided are consistent. RAF conducts ongoing development workshops to build counsellors' skills and knowledge, and the coordinator organizes monthly meetings to update staff and discuss critical cases encountered in the counselling sessions.

Once a volunteer has completed this training, he/she becomes part of the volunteer counsellor pool. All hotline volunteers must abide by the RAF

policies that were developed to reinforce professionalism among counsellors. The RAF code of ethics has been adopted from that of other hotline facilities such as the San Francisco Hotline, and its primary policy is the upholding of confidentiality and anonymity. Care is taken to avoid having callers develop a dependency on any given counsellor—counsellors use code names and will refer callers who need face-to-face counselling to a counsellor who specializes in that skill.

### **Development of materials**

RAF has developed extensive training materials for its own workshops as well as for others it has conducted. For example, in 1995, RAF was tapped as a technical agency to conduct counselling training workshops for agencies such as the Department of Health and fiscal umbrella organizations such as Philippine HIV/AIDS NGO Support. The Foundation has also developed a *Sourcebook on hotline HIV/AIDS/STI telephone counselling* to provide standardized information on issues relating to HIV/AIDS and STIs.

### **Challenges**

A sustainable hotline project requires: a reliable, affordable and accessible telecommunications system; the ability to attract and retain good-quality counsellors and provide them with initial and ongoing training; effective, innovative and sustained communication strategies to raise community awareness about the project; and a viable, long-term funding strategy. The RAF AIDS Hotline has met with some setbacks and learned valuable lessons in the course of trying to meet these needs.

### **Funding priorities and volunteer training**

As national priorities for HIV/AIDS-related funding allocations moved away from the focus on information, education and communication in the early 1990s, the Foundation shouldered more of the financial burden of running the hotline—for example, when the multimedia awareness campaign of 1994 was suspended, as discussed above. RAF had hoped that forging alliances with private industry could provide a source of direct or in-kind financial support, but this has proved to be difficult, particularly in view of the economic crises. For example, at one point, RAF went into partnership with a privately owned cellular phone company that provided all of its customers with toll-free access to the hotline. This generated 20–30 calls per month for the first three months, but when

RAF's primary contact within the company resigned, interest in the joint project lapsed and, after a year, it was discontinued. This potentially successful initiative should not have been embarked upon without equally strong long-term commitment from both agencies.

Approximately 80% of the hotline budget is met by project-specific donor support, with 20% coming from RAF's general operating funds. When donor funding has been curtailed or unavailable, RAF has had to cover the hotline expenses. Moving from the 80-hour training model to the 30-hour Buddy System reduced the cost of counsellor training and reduced the hotline's overhead<sup>22</sup>. All in all, the Buddy System is a workable, cost-effective alternative. It is well suited to the young professionals who make up a large proportion of trainees; they easily learn from the assigned modules, and the shorter, more flexible hours better accommodate their schedules. However, the Buddy System has not been as effective as the earlier training in building a team of highly effective counsellors. Buddy System training takes fewer hours because it relies, in part, on the trainees' initiative to complete 'homework' assignments before the next meeting. When some do not, it flattens the learning curve for everyone at the meeting. The 80-hour workshop was highly participatory and allowed for more individual interaction, and the longer hours spent in the company of all 20 trainees built a spirited team. None the less, like their predecessors, the Buddy System trainees have to pass the examination and perform well on mock counselling calls before they can begin answering hotline calls with their more seasoned buddy.

### **Volunteer turnover**

The volunteer pool is comprised largely of young professionals whose personal career priorities often take precedence, so there is a high turnover among counsellors. On average, a counsellor stays six months to a year (two years or more is rare) and may work as few as two, or as many as 20, hours or more a week. No set number of hours is required of them, and this may be one reason that 'burnout' is more a problem among hotline staff members than among counsellors. The crank and obscene phone calls that can demoralize hotline counsellors are not a significant problem at RAF and comprise only 5–10% of calls. Counsellors learn to deal with such calls at role-play workshops and are encouraged to discuss them at counsellors' meetings and with supervisors.

<sup>22</sup> RAF's budget dropped from PhP1.5–2 million/year (US\$30 000–35 000) to an average of PhP1 million/year (US\$20 000–25 000) after switching to the Buddy System.

Motivating counsellors to stay as long as possible is crucial. Good initial screening for commitment can help reduce turnover. A system of signed contracts and memoranda of agreement can help make volunteer participation more binding. It is also important that counsellors not feel overwhelmed by the seemingly vast amount of information they need to absorb in order to get, and stay, up to date on the wide range of reproductive health issues covered on the hotline. Proper pacing of information input can avoid discouragement. Finally, RAF provides volunteers with the compensation/benefit package outlined above and makes a point of providing ongoing support and recognition for volunteers' untiring efforts. For example, distinguished counsellors are honoured at the end of each year. These efforts and how volunteers are managed administratively should be subject to ongoing review for improvement, but RAF has found that high volunteer turnover is simply a reality that must be faced. RAF has hired an assistant coordinator who, among other duties, can take on volunteers' responsibilities when the hotline is short-staffed.

### Promoting the hotline

It is important that hotlines be advertised regularly and widely. In RAF's experience, massive multimedia campaigns are the most effective (and most expensive) way to promote use of the hotline. In 1994, the national

government's multimedia campaign triggered the great majority of hotline calls at the time. When the campaign

ended, the total number of calls decreased and RAF developed strategies to rekindle interest. In addition to the usual promotional materials (posters, flyers, leaflets, brochures), a cost-effective strategy that worked well was a sticker bearing the hotline number posted in

every telephone booth. These were effective but, after two years, the telephone company implemented a policy to remove them.



Hotline stickers from Remedios

Another cost-effective way to promote the hotline is to have staff appear as guests on radio and television shows. This generally increases the number of calls for one-to-three weeks afterwards. RAF's most effective use of radio has probably been the partnership with 'The Naked Truth', discussed above. Other effective approaches include partnerships with cable channels that provide free community billboard announcements, the use of free tabloid advertisement services and encouraging press coverage, particularly if it raises controversies that will stimulate interest in discussing HIV/AIDS.

As became evident when the hotline number was changed to seven digits, good recall of the number is crucial and must be promoted. Short, catchy statements have also proven effective. For example: '*AIDS Huwag mong Katakutan*' ('Do not fear AIDS'), 'Women are more at risk of getting HIV/AIDS', 'HIV/AIDS: Learn the facts, know one's risks', all followed by, 'Call the Remedios Hotline', and the number.

## Lessons learned

The hotline project provides an efficient information and referral service that networks with a wide spectrum of other service agencies. Because it addresses not just HIV/AIDS but a range of reproductive health issues, callers can discuss a number of interrelated issues and concerns with a single call. The hotline project attempts to maximize the effectiveness of volunteer training by continuing to build the capacity of those who make a long-term commitment and by giving them preference when hiring paid positions. Ongoing use is made of the hotline data as a tool for assessing callers' changing needs and their perspectives on evolving issues. This provides insight on how programmes, too, should evolve, and spurred the establishment of both Clinica Remedios and the Youth Zone.

That volunteers, donors and clients have sustained the hotline project for the past 10 years demonstrates its effectiveness in meeting clients' needs. Although a formal impact evaluation has not yet been carried out, the following can be considered meaningful indicators:

- roughly 10–20% of callers call back with follow-up questions about their original concern;
- some 5–10% of callers call back to express their gratitude for the service;

- 90% of callers referred to RAF clinics for medical services follow through on the referral; and
- the hotline project has gained merit and recognition at the community level, including two prestigious awards.

The hotline project is still dependent on donor support, which is becoming increasingly limited. Creative mechanisms to ensure continuing operations are being investigated—for example, hiring out RAF’s services as a technical agency to conduct counselling training workshops. The hotline introduced the Buddy System in the interest of sustainability and, though not ideal, it has proven to be a viable training system that reduces overhead and ensures that training workshops will continue even if funding is restricted. Finally, additional donor agencies are being approached to support the facility.

That the hotline has been able to sustain volunteer interest and commitment, build and then re-build a significant caller base, dramatically increase the number of female callers and initiate new, successful projects based on caller concerns all attest to its relevance to its community. Callers’ expressed needs and interests have always set the direction of the hotline service, which is why the topics addressed and services offered have expanded well beyond providing basic HIV/AIDS information.

The hotline project protects caller anonymity and confidentiality at all times, and counsellors are bound by a code of ethics, which they discuss at training workshops. Understanding the essence of volunteerism and the importance of participatory consultations is also part of counsellors’ ethical training.

## **Contact information**

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# TARSHI: Talking about Reproductive and Sexual Health Issues

## India

Surface area (square km)	3.29 million
Total population	998 million
Urban population	28.1%
GDP per capita (PPP* US\$)	2248
Life expectancy at birth (years)	62.9
Infant mortality rate (per 1000 live births)	70
Adult literacy rate (>15 years)	56.5%
Adult HIV/AIDS prevalence (15–49 years)	0.70%
Adults and children living with HIV/AIDS	3.7 million
Telephones (mainline and cellular, per 1000 people)	28
Internet hosts (per 1000 people, year 2000)	0.1

\* Purchasing power parity

Estimated figures from 1999, where nothing else is indicated.

Sources: *Human development report 2001*, UNDP.

*Report on the global HIV/AIDS epidemic, June 2000*, UNAIDS.

*World development report 2000/2001*, World Bank.



## HIV/AIDS in India

UNAIDS estimated that at the end of 1999, 3.7 million adults and children in India would be living with HIV/AIDS. On this vast continent, with a population of more than 1 billion people, even low levels of infection add up to huge numbers. The first case of AIDS in India was detected in 1986; since then, HIV infections have been reported in all the states of India. The epidemic continues to shift towards women and young people, with an accompanying increase in vertical transmission and pediatric AIDS. The prevalence of the infection in all parts of the country highlights the spread from urban to rural areas and from high-risk groups to the general population. Migration of labour, low literacy levels leading to low awareness, gender disparities, and prevalence of STIs are some of the factors attributed to the spread of HIV/AIDS.

India is one of the few countries that initiated HIV-prevention activities in the very early stages of the epidemic, and the country has maintained its commitment to prevention efforts. However, due to the vast size of the country, there are many challenges involved in expanding the high-level commitment to all states and to the grass-roots level. One reaction that has been slowing the response to the epidemic was public denial that 'ordinary' people might engage in sexual practices that would increase their risk of HIV infection.

The median HIV prevalence rate among antenatal clinic women tested in the major urban centres of Delhi, Kolkata and Mumbai has increased from 0% in the late 1980s to 2% in 1999. Outside the major urban areas, median HIV prevalence among antenatal women tested in 1999 was 0.3%. More men than women are HIV-infected in India. Among sex workers tested in Mumbai, HIV prevalence had reached 51% in 1993. In Kolkata, 12% of sex workers tested in 1997 were HIV-positive.

In 1995, HIV testing of truck drivers at nine sites revealed 2% of drivers to be HIV-positive. In 1996, 6% of truck drivers in Namakkal and 5% in Tiruchirapalli were HIV-positive.

In parts of north-east India, widespread injecting drug use provided an easy early entry-point for HIV. In Manipur, the prevalence of HIV infection among injecting drug users (IDUs) shot up from virtually nothing in 1988 to over 70% just four years later, and it has remained at these high levels ever since. In 1999, 68% of IDUs in Churachandpur and 49% of

IDUs in Imphal tested HIV-positive. Predictably, since almost all IDUs in the state are men, HIV then spreads to the men's wives and girlfriends through unprotected sex. Around 2.2% of pregnant women in Manipur tested positive for HIV in 1999.

In 1992, the National AIDS Control Organization (NACO) was established to coordinate an enhanced HIV/AIDS programme. NACO provides a national leadership and facilitated the development of State AIDS Societies in all states across India. NGOs are also involved in the work on HIV/AIDS and carry out important prevention and care activities.

## **Telecommunications overview**

There are about 40 million telephone connections, 4.5 million cell phones and 740 000 urban public call offices serving India's population of over 1 billion people. Thirty-eight per cent of villages remain uncovered by telephone service. Thus, telephone access throughout the country can be moderately-to-severely restricted for a large portion of the population. In addition, telephone lines often do not work properly for a variety of reasons, including extreme summer heat.

## **A brief history of TARSHI**

Based in New Delhi, TARSHI (Talking about Reproductive and Sexual Health Issues), began its telephone helpline (the core of its activities) in February 1996. TARSHI began as an individual fellowship project supported by the MacArthur Foundation and grew into an organization that was also supported by The Ford Foundation. Over the past five years, TARSHI has expanded its activities beyond the helpline and is recognized as one of the few organizations in India that addresses issues of sexuality from a rights' perspective. The project continues to be supported primarily by grant funds from donor organizations, with some additional money raised from the sale of its books and other publications, sessions conducted in schools, research, etc.

TARSHI is guided by the vision that all people, whoever they are, have the right to a life of dignity, which includes the right to sexual well-being, based on a healthy, enjoyable and self-affirming sexuality. TARSHI's work currently includes three broad programmatic strands: building the capacity of young people and encouraging new leaders in the area of sexuality; enhancing the quality of helpline services on issues relating to sexuality; and making a larger positive impact in the realm of sexuality.

## Major elements of the project

TARSHI operates two helpline phone lines from 9am to 5pm, Monday through Friday, and provides confidential services in Hindi and English, with guaranteed anonymity. The helpline service is free, though the calls to it are not toll-free. It is supervised by a qualified clinical psychologist and has four counsellors who speak with callers about concerns as wide-ranging as body image, masturbation, contraception, abortion, HIV/AIDS/STIs and sexual abuse. All TARSHI staff members are paid.

Over 45 000 calls have been logged since February 1996. The amount of time devoted to each is flexible and can range from one minute to an hour. The callers are from diverse socioeconomic backgrounds and have ranged in age from 7 to 70 years, though the majority are between 18 and 35 years of age. Over one-third of callers call back. The great majority (75–80%) are Hindi speakers. As the helpline is run in Delhi, most callers are from in and around the city, but there are also many callers who have migrated from rural areas to the city, yet still have their roots in rural India<sup>23</sup>.

Approximately 80% of helpline callers are men, despite the fact that the line is meant to be especially for women. Although in India neither gender has easy access to information, women are more disadvantaged in that regard, yet they bear the greater burden in terms of sexual and reproductive health problems. Devising ways to increase the number of women callers has been an ongoing challenge.

Designed to be interactive, non-judgemental and non-threatening, the helpline offers information that is relevant to the contexts of people's lives, and counselling that explores with callers the pros and cons of particular choices (while never taking from them their own right of choice), as well as referrals to appropriate agencies. The referral network includes private practitioners, government hospitals, therapists and lawyers, as well as HIV counselling, testing, care and support services, etc. The service organizations are researched to the best of TARSHI's abilities, and site visits are made in an attempt to ensure good-quality service—or at least to know first hand what callers will encounter at a facility. In the case of private doctors and therapists, the organization tries to select sensitive and non-judgemental professionals, and asks them to reduce their fee for TARSHI clients.

<sup>23</sup> No significant difference has been noticed in the nature of concerns expressed by people from rural and urban backgrounds.

TARSHI has found that people often do not consult experts about a problem because they are unclear about the procedures or techniques that will be used and the cost of the services. Based on the site visits, TARSHI's counsellors offer simple, comprehensive information on what callers can expect if they follow through on a referral. TARSHI's philosophy is that all people are able to make choices, and helpline information, counselling and referrals can enable them to discover what they want to do. In TARSHI's experience, once callers make a decision, they want to act on it.

Every effort is made to create and preserve a sense of safety for callers. No personal identifying information is requested and care is taken to avoid asking questions that might seem intrusive. No one other than the helpline staff is allowed into the helpline room while calls are in progress.

Although no personal identifying information is gathered, the helpline does document each call and tracks repeat callers using code numbers<sup>24</sup>. The information gathered is used for a variety of purposes. Callers' concerns and queries have formed the basis of TARSHI's print materials and presentations. Logging the time, day and nature of calls lets staff know when to expect a higher number of certain kinds of calls, and this has helped to set the helpline hours. For instance, TARSHI does not operate the helpline on government holidays because very few people call on these days due to the lack of privacy at home. During other periods of infrequent calls (vacation time, school holidays, periods when there is little publicity of the service), the helpline remains staffed and counsellors do off-phone tasks. The documentation also reveals what advertising is effective and how to time promotional campaigns for phased results. The helpline records are confidential and are kept in a safe place.

### **Recruitment, training and support of counsellors**

TARSHI counsellors are women with post-graduate degrees in the social sciences; they range in age from 25 to 35 years. The helpline team and the administrative staff assess new candidates on a number of criteria including sensitivity, openness, awareness of, and comfort in dealing with, issues of sexuality, and fluency in Hindi and English. The hiring

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<sup>24</sup> Callers who are likely, or need, to call in again are given code numbers. This makes it easier to track their calls and ensures that they speak to the same counsellor, if possible. This way, callers who discuss emotional and relationship problems do not need to repeat what they have already said about themselves and their situation.

is done collectively because it is important that the helpline staff feel comfortable with the new person.

New counsellors undergo 8–10 weeks of intensive training that focuses on imparting factual information and building counselling skills. Counsellors are trained on basic sexual and reproductive anatomy and physiology, pubertal changes, conception, contraception, sexual practices, sexual problems, infertility, STIs, HIV/AIDS and other topics. Gynaecologists, sex therapists, STI specialists and other resource persons with relevant skills conduct this training. Additional training addresses issues relating to sexual and reproductive rights, gender, patriarchy, violence against women, the socioeconomic impact of HIV/AIDS, stigma and discrimination, and the rights of people with HIV/AIDS and of other marginalized communities, such as people with disabilities. As a part of their ongoing work, and continuing even after the formal training period ends, counsellors are encouraged to read about, and analytically discuss, different perspectives on these issues. Because people engage in a wide range of diverse sexual acts, the counsellors must also be familiar with the repertoire of human sexual behaviour and know the terms (including slang) that people use to refer to sexual practices.

The counsellor training is done through experiential and interactive role-plays and mock counselling sessions. Counsellors learn to communicate effectively in jargon-free language without preaching or assuming responsibility for callers' decisions. They develop the ability to make referrals in a manner that does not make a caller feel rejected by the helpline. They also learn to identify and deal with crank and abusive calls politely and firmly, while also making the purpose of the helpline

clear to these callers in case they have a genuine problem that they might wish to discuss.



**A counsellor at TARSHI responding to a caller**

### **Counsellor Ayesha reflects on her job**

“Having lived within the confines of a society that views its women as ‘lesser’, gender biases and prejudices have had an effect on innumerable aspects of my life, as well as the lives of women whom I have known intimately.

“My work has been my effort to remedy the vulnerability that women all over the country battle with daily. Providing them with a medium to share their thoughts and fears, to acquire information about their rights and choices, has been the driving force in my life.

“I have realized the magnitude of the task I have set for myself. Initiating social change involves creating awareness among both women and men, in the hope that their attitude towards women’s sexual and reproductive health will change.

“Unfortunately, my experience has been that women are a difficult group to access, for a number of reasons, among them the constraints of the chosen medium—the telephone. It is impossible to ensure that the caller has utilized the information, he or she being a person one never meets and will probably never hear from again. Personally, this has often left me frustrated, making it difficult to assess the extent to which I have achieved my vision. I do, however, feel undeterred as I continue to share and provide information to callers.”

Because issues of sexuality are complex and intimate, these training sessions often trigger strong reactions, and it is important that counsellors become aware of how they feel about charged issues such as sexual violence, for example. Training exercises are conducted for the counsellors to clarify their personal values so they do not unwittingly impose them on a caller. Counsellors can influence callers not only by what is said but also by how it is said, and they have to be particular in terms of the words and phrases they use. For example, counsellors learn to use the term ‘partner’ rather than boyfriend, girlfriend, husband or wife. This makes callers feel more comfortable discussing homosexual, premarital or extramarital relationships. Counsellors also receive voice training, recording themselves in mock counselling sessions until they can speak in well-modulated tones.

After trainees become proficient at professionally and sensitively handling mock calls, they take calls on the helpline under supervision and are given regular feedback on their skills. After about four weeks, a new counsellor is usually able to respond to calls without supervision. But even when supervision may no longer be needed, support is always available. There are always two counsellors in the helpline room, and if one is free she is available to assist the other—especially with ‘difficult’ calls such as those about sexual abuse or suicide.

Counsellors' skills and performance are formally evaluated biannually by their peers and their supervisor. Informal evaluation (e.g., discussing the day's calls) is ongoing.

### **Development of material**

TARSHI documents each helpline call and studies the language male and female callers use to describe their bodies, their sexual experiences and partners. This gives the counsellors a unique insight into Indian men's and women's understanding of healthy sexual behaviour, and the organization uses this information to support its other services to clients and the larger community.

From the helpline experience, it has become clear that, although people need to be able to speak openly about issues related to sexuality, there is also a great need for written material that provides accurate information. The TARSHI books and pamphlets on sexuality have been written in an easy-to-understand and friendly style. Based on analysis of young people's calls, TARSHI has produced a set of informational books on sexuality in English and Hindi that address their specific concerns in an affirmative manner. The books are widely circulated and are being translated into regional languages by organizations that have found them useful. These and TARSHI's other publications are developed for specific audiences based on their concerns as revealed on the helpline. All TARSHI publications affirm people's right to sexual well-being.

TARSHI also makes oral and written presentations on issues of sexuality, reproductive health and HIV/AIDS to professional audiences nationally and internationally. For example, on the basis of the concerns voiced by young people on the helpline, TARSHI makes a case with schools, other NGOs and the media for providing adolescents with sensitive and accurate information on sexuality and HIV/AIDS.

TARSHI also plans to facilitate the development of training materials for helpline staff that will be specific to the Indian context. Most of the available helpline counsellor-training curricula were developed for use in industrialized countries, and they do not necessarily provide responses appropriate for a counsellor to offer to an Indian caller.

## Challenges

### Limitations of telephone technology

Due to India's restricted telephone access, the helpline has timed its hours of operation to correspond with most people's office hours; they find it convenient to call from their workplace if they do not have a phone at home<sup>25</sup>. Restricted access to telephones and/or privacy when making a call can be a challenge to people who need to call the helpline. Many people in India are still unfamiliar with telephone technology (some callers have to ask someone else to dial the number), and may hesitate to speak to an unfamiliar, faceless person about intimate and important issues. Also, many women cannot call because there may be no telephone in their homes and a public telephone booth may be inaccessible and/or considered an uncomfortable place from which to call a sexuality helpline. Indeed, long queues at public telephone booths can not only diminish privacy, but can also lead callers to rush through their call instead of asking questions at their leisure.

If the timing of promotion campaigns is not properly optimized, the helpline can become flooded with calls in response to ads. Not only are callers who get a busy signal discouraged from calling back, but those who do get through complain about how difficult it was. Many people have wondered why TARSHI does not use a system of pre-recorded messages to provide accurate and understandable information to individual callers. This would save on human resources and make it possible to respond to a larger number of calls, but speaking one-to-one about sensitive topics and addressing callers' doubts as they arise is far more effective than having them repeatedly punch buttons and still not find information that is relevant to their concerns.

Another telephone technology that TARSHI has considered and rejected is adoption of a toll-free call-in line. The bureaucratic procedures involved in setting up such a line have deterred TARSHI from seriously considering it. In addition, the cost of making a local call is not very high and is affordable for most of those women who are able to access telephones.

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<sup>25</sup> However, these hours are not convenient for school and college students who are only free in the evening. If there were no staffing or finance constraints, the helpline hours would ideally be till 8pm so that people returning home after college/work could also access the service.

**Increasing the number of female callers**

TARSHI's policies are formulated with women in mind, yet only 20% of the calls are from women, and increasing the number of calls from women remains the greatest challenge. In the first year of operation, the helpline had men as well as women working as counsellors. However, many female callers would terminate the call upon hearing a male voice. This was probably related to cultural taboos that make it difficult for women to speak to men about intimate issues, especially those relating to sexuality. Men have no comparable problems speaking to female counsellors. Helpline promotion strategies have been specifically geared to reach out to women. Advertisements have been placed in women's magazines, and the text of radio and TV advertising uses the feminine gender and is recorded by women.

Women working at home can learn about the helpline's existence only if they have access to radio or TV and are tuned in when TARSHI's advertising is on the air. Many women do not have a telephone at home and may not have the freedom to call from an outside box. Indeed, women may find it difficult to decide to call at all, even if a telephone is readily available, for they are socialized to remain silent about their sexuality and to leave all such matters to men.

**Promoting the helpline**

Documenting how callers heard about the helpline helps TARSHI analyse its advertising so it can be done in a phased manner that results in an optimal number of calls over a sustained period, rather than a barrage of calls intermittently. The helpline has been advertised on a popular FM radio channel, on a local cable TV channel, in a newspaper and in a women's magazine. The phased campaigns on FM radio, in which the advertisement spots are spread out over a period of several weeks, have proven to be the most successful. The time slots are carefully chosen (in the afternoons) to reach as many women and young people as possible. For example, one year, the campaign began with a regular airing of 30-second spots for a week, followed by 10-second spots the following week, and so on. Another year, the spots were gradually decreased over a period of several weeks, which helped get maximum mileage from a limited budget. Interestingly, just learning about the helpline through advertising may not be a strong enough incentive for many people. More than one-third of callers say that, though they heard about the helpline through an advertisement, they were motivated to call when a friend recommended that they do so.

### **Crank/abusive calls**

While often rewarding, helpline counselling can also be stressful. Crank and abusive calls can increase the stress and lead to burnout. Such calls are an occupational hazard on any helpline, but are all the more so when issues of sexuality are the topic. Because Indian men are not used to open discussion on these topics, some of them assume that a woman who talks about them is sexually available. Counsellors are trained to handle such calls by describing the helpline's purpose and emphasizing that it is not a chatline, sex line or a party line offering sexual services.

Some 10–15% of calls fall into the crank/abusive category, and counsellors give callers the benefit of the doubt (though at the cost of feeling abused by the 'borderliners'). These are callers who seem 'genuine' at first and appear to want information and counselling for their problems, but who, well into the conversation, begin to get sexually aroused and/or ask for details of the counsellor's sex life or make her propositions. The counsellors are trained to judge when to terminate the call. On terminating, they suggest that the caller call back when able to concentrate on the conversation and not misuse the helpline. These calls take a toll. As one counsellor put it, "*Cranks and the out and out abusive calls are easy to handle; it's the 'borderliners' that are the worst*".

### **Minimizing staff turnover**

Helpline work is emotionally taxing, and stress builds up from difficult-to-handle calls as well as from the boredom of dealing with monotonously repetitive calls. Stress can lead to burnout, which can have a negative impact on service quality and can lead to high rates of staff turnover. Keeping the lines of communication open, building strong staff relationships and encouraging counsellors to participate in activities such as workshops and conferences that involve meeting others in related fields and sharing experiences can all help prevent burnout.

Counsellors and their supervisor discuss calls (including their emotional responses) and give feedback on an ongoing basis. This interchange helps both to evaluate the service and to prevent burnout.

Even though TARSHI was aware of the dangers of burnout and has had some of these prevention activities in place from the beginning, it has lost a couple of counsellors to burnout over the past five years. But burnout-related turnover has not been very high, and this is an encouraging indication that TARSHI's activities to prevent it have been successful.

**Data collection**

Empowered decisions about sexual and reproductive health do not happen in a vacuum but within the complex context of people's lives. For this reason, information alone, no matter how good, is not sufficient to empower wise choices. Those who look to provide accurate information and to influence people's sexual practices need to know not only who does/uses what, but also why, how, when, for what purpose and to what effect.

Unfortunately, there is a lack of systematic research and documentation on sexual practices and preferences. This stems largely from methodological constraints on eliciting deeply personal and intimate details while, at the same time, ensuring confidentiality and maintaining the dignity of the respondents. None the less, qualitative data that may be meaningfully interpreted and, most importantly, applied in the designing and implementing of programmes are essential.

**Evaluating the programme's effectiveness**

It is very difficult to directly track the effectiveness of a helpline service. Numbers of incoming calls can be purely a function of effective advertising and are not an indicator of the quality of the helpline service. The fact that it is difficult for helplines to directly follow up on callers is a weakness within the service. There is no way to assess the impact of the helpline on callers' risk-taking behaviour or to determine if referrals were followed up on and if callers received satisfying, good-quality service. The lack of direct follow-up also prevents counsellors from knowing the results of their work.

Evaluating the impact of the helpline is therefore based on indirect inferences from the calls, especially those from repeat callers. Reliable indicators of good helpline service can be found in the number of repeat callers, whether their concerns or questions indicate that they understood the information they received during previous calls, whether their sexual behaviour or their feelings about it have changed, and whether new callers were urged by their (satisfied) friends to call in.

For example, frequent callers often move from wanting basic information on sexuality to discussing more complex issues. Over a number of calls, they may move from wanting to know about the sexual transmission of HIV to asking questions about safer sex and how they can have safe, yet pleasurable, sex. From the documentation of their calls, TARSHI has been able to track the positive changes they make in their lives. For ex-

ample, young men report delaying penetrative sex, masturbating instead of visiting sex workers and adopting other less risky sexual practices.

## Lessons learned

Training and competence-building are crucial to providing good-quality service. The field of sexuality is complex and linked to many other issues such as human rights, gender, sociocultural factors and, of course, health. Counsellors who understand these links have a better understanding of sexuality and provide more effective helpline services. An awareness of these links also helps counsellors understand that there is no one 'type' of person who will use the helpline service, and significant subgroups, such as people with disabilities, may always be represented among the callers. It is also important to keep abreast of social change, media coverage of events/issues, and developments in fields such as reproductive technologies.

Having and imparting knowledge and information is not enough, however. For both the caller and the counsellor, sexuality issues are highly charged with emotion and influenced by societal and structural factors, and this must be taken into consideration. On the one hand, because the issues dealt with can be complex and personal, counsellors must take care of their own needs in order to avoid feeling tired, frustrated, confused, etc. This is essential burnout prevention. On the other hand, those who work on sexuality issues need to understand that, by the very nature of their work, they are in a position of greater power *vis-à-vis* their clients and ethical standards must be followed.

Finally, TARSHI has learned that counsellors cannot speak effectively about sexual health and safety without also talking about pleasure.

TARSHI counsellors provide callers with as much time as seems necessary to discuss in detail all the issues they want to bring up. The documentation of calls is used to monitor the helpline and gather data, but the information collected is sometimes unavoidably incomplete.

TARSHI makes efficient use of its limited resources, leveraging a budget of approximately US\$20 000/year to cover five salaries, office rental, office equipment, resource material, phone rental and publicity.

The helpline's effectiveness and its relevance are both enhanced by the fact that, in addition to HIV/AIDS information and counselling, callers are able to address sexuality issues not encompassed by services focus-

ing only on HIV. Most people are not able to consistently and effectively adopt safer behaviour partly because they do not understand safer sex messages that do not also talk about pleasure and are disconnected from actual sexual behaviour. Also, the helpline counsellors are familiar with the common sociocultural myths and misconceptions about sexuality and their underlying sources and can therefore address them effectively<sup>26</sup>.

Finding that the counsellors are comfortable with, and willing to address their queries about, sexuality issues, people call back later with additional questions. If the numbers of repeat callers and of referrals by satisfied callers are a reliable indicator, then TARSHI's helpline has been both effective and relevant. More than one-third of callers are 'repeaters' and an equal number say they called on the recommendation of a friend.

In terms of sustainability, the helpline has become self-sufficient over time with regard to training, knowledge and information, and it does not need to depend on external sources for support in these areas (aside from seeking additional continuing education inputs). But given that the helpline service is free and counsellors are paid a salary, the helpline cannot be financially self-sustaining. It will continue to rely on foundation grants for its operating capital, supplemented by income from its books and peripheral services. A helpline requires good planning and assurance of initial support for a substantial period of time because it is unethical to begin such a service and later withdraw it for lack of funds. In the absence of adequate support, a helpline can reduce its hours of operation, number of lines and staff, if need be, and still function.

The TARSHI helpline is based on a sound understanding of ethical principles, and it places a premium on confidentiality and anonymity. The counsellors are trained in ethics and the ethical challenges that they might face in the course of the work. Counsellors maintain clear professional boundaries in their relationships with the callers.

Telephone technology can well be harnessed in HIV/AIDS education and prevention efforts, and the information gathered from a helpline can become a tool for research and advocacy and can spin off into creating other means of public education. This makes it imperative that issues of context, sustainability and ethics are considered before setting up a service that has the potential to change the lives of the people who use it.

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<sup>26</sup> For example, misconceptions about 'semen loss' resonate with notions of vital fluids and energies and, therefore, contribute to the myth that masturbation leads to weakness.

## Contact Information

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**TARSHI bookmark**

## Conclusion

### The experiences of the four helplines

The four programmes described in this document are The South African AIDS Helpline, the National AIDS Hotline of Trinidad and Tobago, the Remedios AIDS Foundations Hotline based in the Philippines, and TARSHI, based in India.

They were chosen on the basis of how well they fit the UNAIDS Best Practice criteria, how well documented the programme had been, the amount of data gathered and how the data were used. More established programmes were given precedence over younger programmes, as a couple of years' operation was not thought to yield enough information.

The four projects included here demonstrate the strong points that have made helplines a success around the globe, highlighting the challenges that helpline programmes may face and illustrating creative approaches to those challenges.

The topics covered include:

- **Staff recruitment, training and retention:** Whether to pay counsellors or recruit volunteers is a major decision. An obvious advantage of volunteers is the financial savings. However, many programmes, such as South Africa's, identified "high turnover of volunteer counsellors" as a principal limitation to the quality of their service. South Africa eventually switched from volunteer to paid counsellors. Remedios AIDS Foundation, on the other hand, has run its 10-year project largely on the strength of volunteer labour. Initial and ongoing training programmes and training materials are structured, provided and often funded differently for volunteer versus paid counsellors. TARSHI's new counsellors, for example, begin helpline training with a post-graduate degree in the social sciences, while, in Trinidad, the criteria for helpline volunteers are "willingness to participate, compassion, the ability to be non-judgemental and open to new information, and being a good listener with a courteous telephone manner".

Through trial and error, many helplines have developed their own training materials to supplement or supplant those available from programmes in the North. Remedios AIDS Foundation has developed an extensive training curriculum and programme for volunteers, and TARSHI plans to organize a meeting of all Indian helpline operators dealing with similar issues to develop materials specific to the Indian context.

One objective of the training is to make sure that counsellors provide consistent information and know the most up-to-date treatment recommendations and information about the disease. All those involved in projects in this study are aware that training has to be an ongoing process, and they provide their counsellors not only with regular updates but also with opportunities to attend workshops and conferences.

Providing the support the staff members need in order to prevent discouragement and burnout is another ongoing challenge, especially as helpline work can be extremely stressful.

- **Balancing the volume of calls with the staff and phone lines available to handle them:** Particularly after increased promotional activity, the number of calls can exceed the operators' ability to respond, and individuals in need of help may be discouraged from trying to call again. On the other hand, when call volume is low, volunteer counsellors may grow discouraged, and paying idle counsellors may not seem justified. Phased promotional campaigns, such as the one TARSHI describes, are a common solution to this problem.
- **Hoax calls:** Callers who "maliciously abuse the service and/or counsellors"<sup>27</sup> are an ongoing problem, whether they call as a prank or to express their prejudice against people with HIV/AIDS, or because they confuse the helpline with a sex line. The latter is a significant problem for TARSHI. Its counsellors "have become highly attuned to the meanings of voice modulation, ways of breathing and other sounds", and attempt to firmly but politely disconnect such callers. The South African helpline reports the greatest problem of all with failed/hoax calls, receiving three such calls for every legitimate call, and their report outlines several possible solutions. Although the number of hoax calls varies from programme to programme, they are always discouraging to counsellors, and programmes continue to seek effective ways to discourage them and/or reduce their impact.
- **Sustaining funding:** All helpline providers have discovered that although helplines may be a less costly way to provide information and counselling than facilities-based services, they are not inexpensive. Particularly because the service provided is usually

<sup>27</sup> As defined by the South African AIDS Helpline.

free, finding sustainable long-term funding is especially challenging. Organizations use a variety of strategies to meet their operating costs—in Trinidad, the helpline volunteers hold benefit parties and barbecues, and TARSHI sells helpline-related materials, such as the informational books on sexuality it has produced for young people. Operating costs tend to increase as organizations become more successful and expand to meet the needs revealed by callers. Remedios AIDS Foundation, for example, has expanded its services to include three clinics and a youth drop-in centre. Available funding may be the strongest influence when deciding whether to provide a toll-free call-in line.

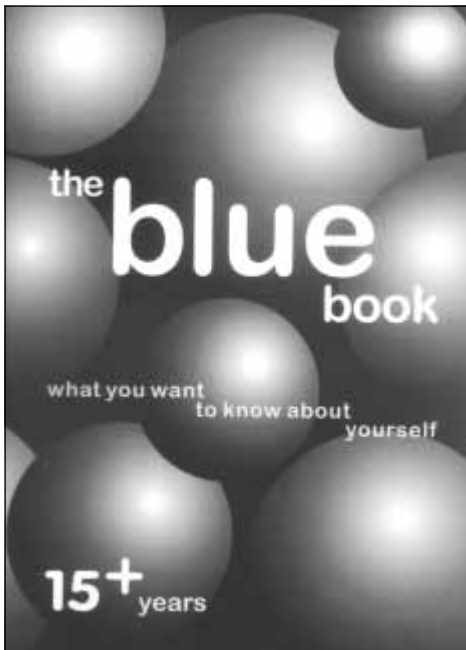
- **Reaching target populations successfully:** Fewer women than men call helplines, including helplines that specifically target women and, in some instances, the discrepancy is startling. The male-to-female ratio that TARSHI experiences, for example, is 4:1. Efforts to analyse and address this problem are often ongoing within an organization and, in this document, both TARSHI and Remedios AIDS Foundation discuss it in detail.
- **Data gathering:** Helpline programmes track call volume and gather demographic data about their callers. The challenge is to gather the optimum amount of data while respecting the caller's wish for anonymity and his/her comfort level. These data support the helplines' efforts to monitor service quality and caller concerns, to strengthen ongoing training and support for counsellors, to identify needs for additional direct or referral services, to track trends in behaviour and to assess the impact of communications campaigns. The helpline in Trinidad, which is closely allied with the Ministry of Health, also uses its data "to advance the national planning efforts in HIV/AIDS prevention and control".
- **Evaluating effectiveness:** A helpline's ability to document and track participants is limited by its commitment to confidentiality and anonymity, and resource restraints preclude follow-up calls. Evaluating a helpline's overall impact is also difficult. It can be expensive to establish baseline data on a helpline's target population, and the limits on client monitoring inhibit evaluating changes in callers' health-seeking or risk-taking behaviour. Remedios AIDS Foundation, which refers callers to its own clinics (or others, if callers prefer), has been unusually successful in tracking callers' use of referral services. TARSHI relies on information

from repeat callers that indicates behavioural change to gauge possible effectiveness. Devising effective evaluation criteria remains a challenge that must continually be addressed, particularly given the usefulness of such data to support funding requests.

Although helplines around the world face similar issues, in too many cases they still operate in isolation. Only rarely are experiences and lessons learned exchanged among organizations, and this limited networking tends to happen on an ad hoc basis by region. Awareness of the importance of national and regional network-building was emphasized at the First European AIDS Hotline Conference (1989) and at subsequent gatherings, but few official networks have been constituted. Since 1991, there have been few large-scale international workshops or conferences specifically addressing the issues facing helplines. This document offers an opportunity for newer programmes to learn from more experienced helplines and to consider strategies that may make their service stronger and more sustainable.

Helplines provide a valuable community service that is frequently overlooked by public health officials and national AIDS control pro-

gramme managers. To truly incorporate HIV/AIDS helplines into the national strategies of low- and middle-income countries, helpline programmes and their friends must document and showcase their successes to government, donors and international agencies. In too many countries, the need for the accurate information, counselling and referrals that helplines can provide remains urgent.



**TARSHI booklet**

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together eight United Nations agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners—governmental and NGO, business, scientific and lay—to share knowledge, skills and best practice across boundaries.

The need for accurate HIV/AIDS information is vital. Around the world, telephone helplines have proved to be an accessible, affordable and acceptable source of HIV/AIDS information, counselling and referrals for callers from all walks of life. First initiated in high-income countries, helplines have expanded into many low- and middle-income countries, particularly as the latter improve their telecommunications infrastructure and identify HIV/AIDS as a pressing social concern.

The great majority of HIV/AIDS helplines are run by nongovernmental organizations, and establishing and maintaining a helpline is a complex task. Yet, although helplines everywhere face similar issues (how to recruit, train and retain staff, devise effective outreach strategies, ensure sustainable funding, gather and apply caller-based data, and evaluate performance and effectiveness), in too many cases, they operate in isolation.

This Best Practice Case Study offers an opportunity to learn from the experiences of well-established helplines in India, the Philippines, South Africa, and Trinidad and Tobago. They demonstrate the principles that have made helplines globally successful, outlining the challenges involved and creative approaches to meeting those challenges.



Joint United Nations Programme on HIV/AIDS

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