

Training HIV Positive People as Advocates

Pacific Islands AIDS Foundation

THE FIRST known case of infection of human immunodeficiency virus (HIV) in the Pacific was reported in the Northern Mariana Islands in 1984. By 2009, over sixteen thousand known HIV positive cases have been reported, with over ninety percent being reported in Papua New Guinea (PNG). By global standards, the Pacific Islands remain a low prevalence region. However, some areas are already facing high levels of infection, and other factors threaten to create conditions for a generalized epidemic in the future. These factors include:

- The large youth population;
- The high incidence of sexually transmitted infections (STIs) and teenage pregnancies;
- Highly mobile populations, both within countries and internationally, particularly for employment;
- Limited access to condoms and to health information, particularly outside the main urban areas;
- Poverty and associated conditions such as low employment;
- Socio-cultural barriers surrounding sex and sex education; and
- Cultural perspectives on the status of women.

A 2009 review of the current state of law in the Pacific in relation to HIV provides some important findings:

a. HIV Testing in the Pacific

With the exception of PNG, which prohibits mandatory testing in most circumstances, there is no legislation restricting mandatory HIV testing. This means that mandatory HIV testing is not illegal in most of the Pacific although it is contrary to international law and practice. There also exist provisions in the employment legislation of various countries (e.g., the requirement of a medical exam) that could be considered a backdoor way of justifying mandatory HIV tests. Prisons, education and immigration legislation also have requirements of medical exams which might include a mandatory HIV test.

b. Health Care

Although international law includes a general “right to access health care,” few if any Constitutions in the Pacific actually recognize this right and in any event, in most - if not all - Pacific countries, health care is not free. Access to the means of preventing the spread of HIV (condoms, education materials) may also be hindered by antiquated obscenity rules and regulations. Most public health legislation in the Pacific makes no mention of HIV, even though Ministries of Health across the region are the department with primary responsibility for dealing with the disease. Most countries have legislation that deals with “notifiable diseases” or “quarantinable diseases” which require mandatory reporting of infection or suspected infection and/or potential forced isolation of those with various infectious, communicable or venereal diseases. At present HIV is not specifically included on most lists, though some countries, such as Tonga, have included it.

c. Education

Few Constitutions in the Pacific actually recognize the right to education. The Marshall Islands and Fiji are exceptions; denial of access to education in these countries may be questioned as a violation of the constitutional right to education. However, it is not known to what extent this right is actually enforceable. Most education legislation in the Pacific addresses neither HIV nor the right to education.

d. Criminal Law

Homosexuality and prostitution are generally illegal in the Pacific region. This contributes to the marginalization and stigmatization of sex

workers and men who have sex with men (MSM) which in turn can discourage these individuals from seeking testing or treatment, and thus increase the risk of HIV infection among the sex worker and MSM population. There is also much controversy in the region surrounding HIV-specific criminal laws. The debate continues over whether willful transmission, attempted willful transmission or reckless transmission of HIV should be unique criminal offences. No country in the Pacific has a specific HIV-related criminal offence, although some, such as Fiji, have considered creating one. However, most countries have other existing provisions that could be applied to willful, reckless or attempted transmission of HIV. Assault causing bodily harm, grievous bodily harm, criminal or common nuisance, criminal negligence and unlawful infection are all examples of offences that exist in the Pacific which could be applied to HIV transmission.

Regional response to the challenges of HIV/AIDS started when the first case of HIV was reported in the early 1980s. But only in mid-1990s that the health ministers of the governments in the region started meeting on the problem and finding resources to address it by linking governments to non-governmental institutions including churches. The regional body, the Secretariat of the Pacific Community (SPC) started developing regional strategies on education and prevention of spread of HIV/AIDS. A 1996 report entitled *Time to Act* provided the basis for the first regional strategy, from 1997 to 2000.¹ The Regional Strategy on HIV/AIDS 2004-2008, adopted by the SPC, recognizes the importance of human rights and the greater involvement of people living with and affected by HIV/AIDS.

It therefore emphasized the need for² respect for human rights in relation to people living with HIV/AIDS. Based on these rights, people living with HIV/AIDS should be actively involved and supported through networks and the interface with mainstream services.

As a result, the Secretariat of the Pacific Community adopted as one of its themes “human rights and greater involvement of people with and affected by HIV/AIDS.”

A Response to the Situation

The Pacific Islands AIDS Foundation (PIAF) responds to the HIV/AIDS situation in the Pacific as well as links to the existing regional initiatives on human rights and the people with and affected by HIV/AIDS. It is a Pacific-

based regional organization for people living with HIV and AIDS (PLWHA), based in Rarotonga, Cook Islands.

PIAF is the first regional civil society organization (CSO) focusing exclusively on HIV and AIDS in the Pacific Islands. A young Tahitian woman, Maire Bopp, one of the first Pacific Islanders to go public with her HIV positive status, founded it in 2002. Her crusade started in December 1998 when, still a university journalism student in Fiji, she broke a taboo in her community by revealing that she was HIV-positive during a Pacific Islands News Association (PINA) conference in Tahiti. Since 1999, after graduating from the university with a journalism degree, she has been touring the islands to speak to communities, schools and nongovernmental organizations (NGOs) about the epidemic. In the same year, she won PINA's Pacific Freedom of Information Award for her outstanding efforts in the promotion and defense of freedom of information and expression in the region.

She changed the shape of HIV work in the region by putting a face to the disease and challenging Pacific political, religious and traditional leaders to respond appropriately to the epidemic.

PIAF has the following goals:

- To improve the quality of life for HIV positive people, their households and families by helping educate them about HIV and how to manage it as well as about their rights and how to exercise them, offering them skills building programs and advocating for their access to quality treatment, health care, social and economic integration, and better legal protection from all forms of discrimination.
- To prevent the further spread of the epidemic in the Pacific region by engaging HIV positive people in the delivery of messages to our decision-makers, policy-makers, youth and other communities, and by mobilizing Civil Society Organizations to unite in building an AIDS-Free Pacific.

To achieve these goals, PIAF has adopted a number of strategies:

a. Positive Living. Throughout the Pacific Islands region, HIV positive people face the stigma and discrimination. Fear of rejection or social exclusion results in many HIV positive people refusing to disclose their status to their families and partners or denying their status. This leads to further isolation and can increase the potential for transmission through high-risk behavior. PIAF seeks the creation of a friendlier environment that makes it easier for HIV Positive people to voluntarily disclose their status with-

out fear of discrimination. This in turn will contribute towards awareness and prevention, an improved feeling of self-esteem, and acceptance of HIV Positive people as valued members of society. It aims to give HIV Positive people the opportunity to acquire knowledge and skills that will help them improve their self-esteem, live positively with their health condition and face the stigma and discrimination that they may be confronted with. It also aims to raise awareness on positive legal reforms and help governments ensure that the rights of their people living with HIV and AIDS are protected.

b. Positive Health. Without access to proper treatment with anti-retroviral drugs, the progression of the disease from HIV into AIDS is inevitable. Anti-retroviral treatment is the most effective life prolonging strategy known to date; but it has its limitations. It is a constraining regimen that requires good management capacity and ability from the patient. It can cause irritability, depression, hunger, fatigue, skin rashes that encourage people to stop their treatment at the risk of worsening their health and chances of treatment combinations. PIAF will continue to work towards free anti-retroviral (ARV) accessibility in the region and dedicate resources and energy to develop activities that will offer greater mental support and well-being to patients.

c. Positive Action & Prevention. The Pacific region continues to experience political and social upheaval. Now, more than ever, we must build efforts to keep AIDS on government agendas and priorities to secure some of the progress made in fighting the epidemic. It is crucial that we advocate for and support government initiatives in the area of 'best model' policy development, while targeting the media to ensure that the messages are heard in a balanced way. We must also actively maintain training and supporting groups of advocates, comprising of HIV positive people, to advocate for positive actions within their own communities and from their national decision makers. These positive actions include making factual and sensitive information on HIV and AIDS easily accessible to the media who have, for various reasons, played a role in reinforcing the stigmatization and discrimination of the general public against HIV Positive people. The expected result is that messages become, and remain, more sensitive to the issues faced by HIV Positive people and their families and promote their human rights.

d. Positive Partnership. All sectors of society are affected by HIV and AIDS. It is critical that we all participate in the response to the epidemic. We are all losing a relative, friend, colleague or key leadership personnel

and when the infection advances we lose a critical mass of the labor force as is experienced in Africa today. We must motivate players from all levels and sectors of society and encourage everyone to work together. Businesses, churches, trades, professions and public services all need to set up initiatives, and build partnerships inside and across our area.

e. Positive Investment. The economic burden of HIV on HIV positive people and their household is reduced.

f. Positive Management. HIV initiatives are effectively managed and inclusive of HIV positive people

PIAF also serves as the Secretariat for the Pacific Alliance of CSOs (Civil Society Organizations) on HIV & AIDS - a network of partners across the region collaborating to improve actions in response to HIV and AIDS.

Programs

PIAF implements the following programs:

a. Ambassadors Outreach Program. PIAF supports HIV positive people as full-time advocates on issues surrounding HIV and AIDS. AIDS Ambassadors share their testimonies and knowledge with a variety of community organizations including government, health and church groups. AIDS Ambassadors put a face to HIV and help reduce discrimination through the sharing of their personal stories. Many communities throughout the Pacific still perceive the disease as a punishment or curse and the work of AIDS Ambassadors helps to change these perceptions.

b) B.I.B.L.E Project. The BIBLE Project is designed to provide a culturally safe and relevant process for people living with HIV/AIDS (PLWHA) to assist them to Build Incredibly Beautiful Lives Enthusiastically. The Project utilizes a narrative group counseling approach with theological reflection by the participants that is respectful and embraces their culture and faith. Through this approach, PLWHA are given the opportunity to move from isolation to inclusion.

The BIBLE Project is implemented in partnership with the Pacific Theological College based in Suva, Fiji.

c) Discrimination Study. PIAF initiates studies on specific discrimination-related issues. In 2006, PIAF initiated its Study on the Stigma and Discrimination experienced by positive people across the Pacific. The study involves HIV positive people from Fiji, Kiribati, Vanuatu, Samoa, and

Solomon Islands, and is being funded through the Pacific Regional HIV Programme's (PRHP) competitive grant program.

d) *Hardship Grant.* Since 2003, PIAF has been operating a Hardship Grant program that provides emergency or temporary relief assistance to PLWHA who are facing extreme hardship as a result of deteriorating health, and/or discrimination from the community as a result of their HIV status. PIAF has set criteria in administering the grants to provide direct assistance to households and bring about some sustainable benefit to the family.

e) *PIAFilms.* PIAF has produced several documentaries featuring HIV positive Pacific Islanders in an effort to address key HIV issues, break down HIV-related stigma and discrimination, and share the courageous stories of Pacific Islanders living with HIV. Many of these films are available in multiple languages. In a geographically vast region, PIAF uses a multi-media approach to reach isolated islands and to help put a Pacific face to HIV. The documentary series is called 'Positive Lives', and began in 1999 with the documentary *Maire*, a film about the founder of PIAF—one of the first HIV positive people to go public with her status in the Pacific. In 2006, PIAF revived the series with two documentaries named after the women they feature: *Peati*, which is the story of an HIV positive Samoan woman and *Irene*, the story of a Ni-Vanuatu woman. Each film focuses on women living with HIV/AIDS, and highlights the various challenges they face after diagnosis and how hope can be found through family and community support, and access to ARV treatment.

PIAF undertakes education on human rights and the issues impacting people living with HIV (PLWH). PIAF publishes information and education communication materials (IEC's) such as the *HIV and Your Rights* booklet and conducts education workshops. PIAF also utilizes various media platforms for up to date press releases on HIV and AIDS issues in the Pacific region.

AIDS Ambassadors

In December 2003 PIAF started the AIDS Ambassadors training and outreach program. The training gives PLWH the opportunity to gain knowledge and skills to live positively with their HIV status and face the stigma and discrimination they may confront in their lives. It builds the capacity of HIV-positive people to become advocates in their own communities.

The outreach component encourages the formation of strong and effective HIV Positive public advocates and the strengthening of advocacy networks within the region.

PIAF works with existing networks, assists in strengthening organizations with limited capacity and builds those that are non-existent. A particular emphasis is placed on advocates becoming peer educators; working with schools, in church groups and communities to challenge commonly held misconceptions about HIV and AIDS. The AIDS Ambassadors program aims at better-targeted prevention messaging in the community.

Since 2003 PIAF has made significant progress in the provision of sustained and ongoing support and resources for AIDS Ambassadors.

Temo Sasau, employed as PIAF's AIDS Ambassadors Coordinator since 2008 and based in Lautoka (Fiji), has played a significant role in growing the membership of the AIDS Ambassadors and supporting those who have become public advocates. Requests from community groups for AIDS Ambassadors have been numerous and the responses, as the following quote from a participant demonstrates, have been overwhelmingly positive.

We had a combined session on HIV/AIDS, its effects, how it is transmitted, with teachers of Vatukaloko Junior Secondary and Drauniivi District School. The presentation was lively and also very emotional and interesting and motivating. We need more of this type of presentation. - School Principal, Vatukaloko Junior Secondary School

In the past twelve months AIDS Ambassadors have organized and conducted Regional Life Skills Training, including the BIBLE project, with participants from Fiji, Samoa, Solomon Islands and PNG and English Literacy and Computer Skills with participants from Fiji, Samoa, Solomon Islands and Papua New Guinea (PNG). The AIDS Ambassadors trained four PLWHA on HIV/AIDS and specific Human Rights; presented submissions at the International Congress on AIDS in Asia and the Pacific 2009 (ICAAP); supported the May Candlelight Ceremony; publicly advocated for The World Testing Day campaign; attended legal training sessions; took part in various public speaking engagements; conducted home visits and contributed their stories to a wide variety of Information and Education Communication mediums.

In the Field

Several AIDS Ambassadors are now working in several countries in the Pacific. In Fiji, Paulini Vakacegu is now working fulltime with the Pacific Counselling and Social Services (PCASS) as a Trainer/Counsellor. In Solomon Islands, Alice Buko has been working with local positive people with a view to setting up a local support group. She is also scouting potential participants for the upcoming BIBLE. So far Alice has had discussions with two positive people. In Vanuatu, Irene Malachi has just returned from an outreach activity on Santo Island.

Temo Sasau will be visiting the Solomon Islands, Kiribati and Samoa in 2010 to evaluate newly trained AIDS Ambassadors, discuss plans with the Red Cross about setting up and hosting PLWH Support Groups, visit in-country PLWH, and liaise with Ministry of Health representatives in regard to complaints of inadequate HIV drug services.

The AIDS Ambassadors hold training activities for those who may become AIDS Ambassadors themselves. Table 1 presents a module of the training.

Table 1. AIDS Ambassadors Training Module

Day One	Day Two	Day Three	Day Four	Day Five
Session A Welcome and Introduction Course Overview and ground rules Motivation What makes a good Speaker Elements of Good Storytelling	Session A Welcome Voice work Style of Talks	Session A Common Questions and Sample Answers	Session A Why positive people speak out Who discloses their status in public? Motivation of positive speakers Protecting Human Rights and Promoting Public Health Benefit to the community Negative consequences of speaking out Benefits to the speaker	Session A Joining the Regional AIDS Ambassadors program

Table 1. (cont'd) AIDS Ambassadors Training Module

Day One	Day Two	Day Three	Day Four	Day Five
Session B Body Language What is important for you Structuring Talks	Session B Continue sample talks	Session B Knowing our rights as human being	Session B The first steps Support for speakers Positive peers Family Counselling: Guest Speaker: Steven Vete	Session B Avoiding Burnout – Stress management
Session C Handling difficult situations Encouraging questions	Session C Dealing with the Media	Session C Being in control of your health: ARV and other support	Session C Forming Partnerships Training Becoming an Expert Signing a Contract	Session C Summary of lessons learnt Goal setting Debriefing and Evaluation

Achievements

PIAF has been able to achieve the following:

1. Actions leading to the availability of anti-retroviral treatment in twelve Pacific Islands Countries;
2. Empowering and educating HIV+ People through our AIDS Ambassadors Program and supporting them in educating their communities by publicly sharing their experiences;
3. Increasing awareness of stigma and discrimination against HIV+ People through producing and broadcasting the “Positive Lives” Films;
4. Completing the first survey on the experiences of HIV+ People with stigma and discrimination in the Pacific Region;
5. Promotion of in-country support groups and counselling;
6. Establishing a Regional Hardship Grant for HIV positive people;

7. A review of Law and HIV in the Pacific Islands and production of educational and advocacy materials in a range of Pacific languages.

PIAF's documentaries, *Peati* and *Irene*, won the Peace and Development Award at the Pacific Media Peace Awards. This award went to director and producer Ingrid Leary, an independent journalist who has worked with PIAF on many projects over the years, including directing and producing the films.

Endnotes

¹*The Regional Strategy on HIV/AIDS 2004-2008* (Noumea: Secretariat of the Pacific Community, 2005), page 23.

²*Ibid.*, page 25.