



# INVISIBLE PEOPLE

POVERTY AND EMPOWERMENT  
IN INDONESIA

presented by PNPM Mandiri —  
Indonesia's National Program for Community Empowerment

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Sorong, Papua

## HIGH RISK GROUPS AND A LOCAL EPIDEMIC

Tanah Papua occupies the western half of the island of New Guinea and some smaller surrounding islands. Its geography, history, culture, and economy make it distinctly different from the rest of Indonesia. It covers a huge area and is very sparsely populated. Its people are made up a vast number of different tribes and groups, many with their own languages and cultures. The great majority of these people live in rural and sometimes very isolated areas. In the coastal towns and mining centers, there are large numbers of migrants from Java, Sulawesi, and elsewhere in Indonesia.

Tanah Papua is one of the richest regions in Indonesia. It also has some of the country's direst poverty. Mining and logging operations generate enormous revenues, but almost half the people live on less than a dollar per day. Medical services are often poor, particularly in remote areas. Education levels are much worse than average. Undereducated men and women from rural areas travel to towns and mining centers to earn a living as laborers, often leaving families behind.

In general, Papua has been more severely affected by HIV and AIDS than anywhere else in Indonesia. In the rest of the country, the virus is largely concentrated among high risk groups. In Papua, the disease has become a general epidemic, with at least 2.4% of young adults testing HIV-positive. In the rest of Indonesia, most new cases of HIV result from the sharing of needles by drug users. In Papua, sex between men and women is responsible for more than 90% of new cases.

There are many reasons for the high rate of sexual transmission in Papua. There is a general lack of awareness regarding HIV and how it is transmitted and a low level of awareness regarding the effectiveness of condoms to reduce the risk. Condoms are often hard to find, particularly in rural areas. Many people, especially sex workers, have sex with multiple partners.

Sorong is a large port town on the north coast of Papua, the hub for the region's oil and gas industry. More than half of the people came here from outside Papua. Most of the rest are migrants from rural districts in Papua itself, looking for work. There are considerably more men than women in the town. The town has a large sex industry, with women from Java, Manado, and elsewhere, working from bars, clubs, and brothels. Mainly Papuan women sell sex in parks and on a strip of beach near the harbor. The town has one of the highest rates of HIV infection in the region and, indeed, the whole of Indonesia.

To help those facing discrimination and stigmatization and to provide other services, a group of people living with HIV have established a peer support group called Sorong Sehati. Sorong Sehati was established with some support from the Spiritia Foundation, a Jakarta-based organization that has played a powerful role in developing a network of such groups across the country. In total, it has supported the establishment of at least 64 peer support groups in 27 provinces. Like Sorong Sehati, each of these groups is almost entirely autonomous, established and managed by local activists. However, Spiritia plays an important role by providing advocacy materials and training for these activists. Often, it helps the activists to visit more established groups elsewhere.

At present, Sorong Sehati receives virtually no financial support from the government or from outside agencies. It operates on a tiny budget in premises donated by Yayasan Saint Augustina, a Catholic medical mission managed by Sister Zita Kuswati. In addition to providing a meeting space for the Sorong Sehati peer support group, the mission provides medical services for people with HIV and AIDS.

**Papua has been more severely affected by HIV and AIDS than anywhere else in Indonesia. At least 2.4% of young adults are HIV-positive. Sex between men and women is responsible for more than 90% of new HIV transmissions.**

AIDS was first identified in Indonesia in 1987. By the end of 2007, there were 270,000 HIV-positive people in the country – one in five hundred of the population. In most provinces, the virus is largely concentrated among high-risk groups, such as female sex workers, injecting drug users, men who have sex with men, and *waria*. Among these groups, the nationwide infection rates are 7.1% among female sex workers, 52.4% for injecting drug users, and 5.2% percent among men having sex with men.

After the first confirmed case of AIDS in 1987, the Indonesian Ministry of Health established a National AIDS Committee, which established a series of national action plans. The government's programs focus on prevention through education to raise awareness among the general population and particularly high-risk groups. In some areas, government programs provide condoms and clean syringes. The government also provides funding for antiretroviral therapy (ART), which is intended to be available free of charge through major hospitals.

In fact, ART is readily available only in hospitals in big cities. In December 2006, less than a quarter of people who had advanced HIV infection were receiving ART in accordance with approved treatment protocols. The majority of those receiving this treatment lived in Jakarta. In Papua, only 3% of people with HIV, including those with advanced infection, have ever received ART.

Infection rates are beginning to fall in all high-risk groups across the country except among injecting drug users. The rate of use of condoms by sex workers is improving. However, knowledge regarding HIV and AIDS remains extremely low among the general population throughout Indonesia.

A young AIDS victim.







## Yudhi

I'm HIV-positive. I was first diagnosed in October 2003. When I was younger, I used hard drugs in Makassar. That's where I was born. My family sent me to Sorong to try to clean up and get off drugs. And I did. After I kicked drugs, I read about HIV and AIDS. I wanted to get tested. My sister-in-law was a doctor. She helped arrange the test for me. Then I found out that I was positive. My sister-in-law reacted badly. She was ashamed to have an HIV-positive brother. She thought that if people found out, they'd think badly of the whole family, so she sent me back to Makassar.

My parents didn't cope well either. They didn't know anything about HIV. They were scared. They made me eat with my own cutlery and plates. I wasn't allowed to eat with the rest of the family. If I came into the room and sat down, they got up and moved away. They set aside a separate bathroom for me, which no one else used. I had to wash out of my own bucket. My parents were terrified that other people in the family would find out. At the time, I didn't know much about HIV myself. I went to a self-help group in Makassar. They gave me some information. They explained that HIV wasn't really very infectious. My parents were still scared. In the end, I couldn't stand living at home. I decided to go back to Sorong. I didn't stay with my sister-in-law. I stayed with a friend. I didn't tell him about my status.

I was quite healthy. I responded well to the antiretroviral therapy. I received treatment free of charge through the local hospital. My viral loads were low. My weight was normal. Through the hospital, I started working as a volunteer for the provincial health department's HIV information programs. Eventually I received a small salary. Out of eleven educators in the program, I was the only one who was HIV-positive.

I was sent to Jakarta for training. In Jakarta, I met some people from the Spiritia Foundation. Most of the people at Spiritia are HIV-positive. They operate on the principle that HIV-positive people should help each other. They pushed me to set up a self-help group in Sorong. So together with two HIV-positive friends, I set up Sorong Sehati.

Spiritia told me about a sympathetic doctor in Makassar. I went home to Makassar. With the doctor, I visited my parents. He made them realize that HIV wasn't as infectious as they thought. Their attitudes began to change. They weren't so scared. They still don't want anyone else to know about my status, though.

I'm quite open about my status. When I'm talking about HIV and AIDS, I try to judge the audience first. If I think they can handle it, I tell them about my status. If I don't think they can cope, I keep quiet about it. Sorong Sehati has made people more aware about HIV and AIDS. We had one member, a bank employee, who was HIV-positive. His employer found out. They were scared. They threatened to fire him. Sorong Sehati went to the bank with a doctor. We did a presentation to help them understand. They agreed to keep him on.

People who have just found out that they are positive need to know how to manage HIV. They often think that they can't have children. They think their children will be infected. They worry that they will infect their husband or wife. If you know how to manage the risk, you can prevent that. I'm married. My wife is not HIV-positive. She's pregnant. Before my wife got pregnant, a doctor checked my viral loads. With the antiretroviral treatment, my viral loads are low. That means the risk of infection is low. The doctor calculated my wife's fertile periods. He suggested that if she wanted to get pregnant, we should have sex without a condom once a month during her most fertile period. She became pregnant and she's still negative.

If people living with HIV have accurate information, they know how to cope with their condition. They can handle other people's reactions to it. It's a serious chronic disease, but it isn't that different from diabetes or high blood pressure. The main difference is that people are scared of it.

**"My parents didn't cope well, either. They didn't know anything about HIV. They were scared. I wasn't allowed to eat with the rest of the family. If I came into the room and sat down, they got up and moved away."**







## Sister Zita



Sorong Sehati receives virtually no financial support from the government or from outside agencies. It operates on a tiny budget from premises made available by Yayasan Saint Augustina, a Catholic medical mission managed by Sister Zita Kuswati. In addition to providing meeting space for the Sorong Sehati peer support group, the mission provides medical services for people with HIV and AIDS, as well as other conditions and ailments. The foundation runs a communal garden and has other activities for its patients.

Sister Zita would like to provide more services for people with HIV/AIDS. "If we had more funds, we could build a hospice. It wouldn't cost much. We could buy land or rent on the edge of town. Land isn't expensive there. People with HIV and AIDS who are still healthy would volunteer to work there. It works better when people with HIV and AIDS are involved in looking after themselves."



## ACKNOWLEDGMENTS AND CREDITS

This book was sponsored by the PNPM Mandiri program. The goal of PNPM Mandiri, Indonesia's National Program for Community Empowerment, is to reduce poverty. PNPM Mandiri was established by the Indonesian government in 2007 to act as an umbrella for a number of pre-existing community-driven development programs, including the Urban Poverty Program and the Kecamatan Development Program, as well as a number of other community-based programs that were managed by nineteen technical ministries. By 2009, PNPM Mandiri was operating in every subdistrict in Indonesia.

PNPM Mandiri is committed to increasing the participation of all community members in the development process, including the poor, women's groups, indigenous communities, and other groups that have not been fully involved in the development process. *Invisible People* is one way that PNPM Mandiri can reflect on ways to better include marginalized and excluded groups in development.

Bilateral and multilateral assistance for the PNPM Mandiri program has been forthcoming from a number of donor agencies. The PNPM Support Facility (PSF) was established by the Indonesian government as a means of facilitating the contributions of international donors that support PNPM Mandiri. Contributors to the PSF currently include Australia, Denmark, the European Community, Netherlands, and the United Kingdom. PSF provided financial and other support for the publication of *Invisible People*, in order to raise awareness of the special needs and aspirations of marginalized and excluded groups.

We would like to thank the people who sat down to tell their stories and put their lives on public display for the publication of this book. Across the country, the people who were approached were amazingly open about the most personal details of their lives, their problems, their hopes, and their aspirations.

When they collected these stories, Irfan Kortschak and Poriaman Sitanggang explained the purpose of the project and sought the consent of all subjects. The subjects told their stories, often over several days and during several meetings, after which Irfan attempted to recreate their words in a first-person account that conveyed the individual's ideas, feelings, and voice. In a few cases, subjects wrote their own stories in their own words, which were then edited with the subject and translated. When possible, Irfan provided a written account to the subject so that he or she could check and reconfirm that the account was an accurate representation. Otherwise, he discussed it with them. Subjects were reminded that their accounts would be published and asked to be certain that they had no objection to this. Irfan apologizes if despite this process, inaccuracies or misrepresentations have slipped into the text.

A vast array of people helped facilitate interviews and

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and *Picturing Indonesia, Village Views of Development* (2005).

All the photographs in this book were taken by Poriaman, with the exception of those taken by Irfan on the following pages: female students (p. 37); Ai Anti Srimayanti (p. 43); Heri Ridwani (p. 45, p. 47); Pak Inceu (p. 51); Laminah (p. 70); women's literacy group (p. 72, p. 74); Musinah (p. 73); Kolok Getar (p. 81); Kolok Subentar (p. 83); Erni Bajo (p. 113); Mading (p. 129); harm reduction meeting (p. 131); Benk Benk (p. 133); Apay and Harry (p. 134); Megi Budi (p. 137, p. 139); Rifky (p. 138); and Reza (p. 148, p. 149).

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Irfan Kortschak studied Indonesian Area Studies at the University of Melbourne, and International and Community Development at Deakin University in Australia. He is a writer, translator, photographer, and long-term resident of Jakarta. His previous publications include *Nineteen: The Lives of Jakarta Street Vendors* (2008) and *In a Jakarta Prison: Life Stories of Women Inmates* (2000). He is currently engaged in writing assignments and consultancy work for NGO's and development agencies in Indonesia.

Poriaman Sitanggang has worked as a freelance photographer since 1985. He has held a number of photo exhibits, including *Indonesia - Famous People* (1993), *Batak Faces* (1994), *Dani: The Forgotten People* (1997), *Manila: The City of Contrasts* (1999), *The Song of Arini: The Eastern Indonesia People* (2001), and *Burning Borneo* (1998-1999). His work has appeared in a number of magazines and books, including *Kain untuk Suami* (A Cloth for My Husband) (2004),

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