INVISIBLE PEOPLE
POVERTY AND EMPOWERMENT
IN INDONESIA

presented by PNPM Mandiri —
Indonesia’s National Program for Community Empowerment
INVISIBLE PEOPLE

POVERTY AND EMPOWERMENT IN INDONESIA

Text by Irfan Kortschak
photographs by Poriaman Sitanggang
with an introduction by Scott Guggenheim

presented by PNPM Mandiri —
Indonesia's National Program for Community Empowerment
Makassar, South Sulawesi

SELF CARE: LEPROSY-RELATED DISABILITIES

Leprosy is a bacterial disease that affects the skin and peripheral nerves. Leprosy remains endemic in 91 countries around the world, with 738,284 new cases detected globally in 2000. Around the world, several million people have permanent disabilities and disfigurements related to the disease.

Across Indonesia, the rate of prevalence is slightly under one new case per 10,000 people. This means that there are approximately 20,000 new cases detected each year. However, the rate is considerably higher in some regions, particularly East Java, North Maluku, and South Sulawesi. Approximately 10% of leprosy patients in Indonesia have already suffered significant nerve or other damage prior to the diagnosis and treatment of their disease.

The Jongaya leprosy settlement in Makassar, South Sulawesi, is a community of 2000 people. Of these, about five hundred have suffered from this disease. Most of the others are the healthy wives, husbands, and children of those affected. All the residents with leprosy have been treated for their disease and are considered cured. Even so, many have serious disabilities and horrible disfigurements. Some have had limbs amputated. Others are blind. Many wear prosthetic limbs. Others push themselves around in makeshift carts.

Jongaya is well located and has good facilities. Situated on the edge of town, it has electricity and access to water. People here are more likely to be able to work or beg successfully than in remote rural areas. There, people live in some of the most squalid circumstances and dire poverty in Indonesia.

In the past, lepers were often forcibly quarantined. This is no longer the case. No one is compelled to live in Jongaya. However, many people here have been driven away from their original communities. Others feel shame and leave home to seek refuge with others similarly afflicted.

Living near a large, prosperous city also makes begging more profitable. Some residents of the Jongaya leprosy settlement in Makassar, particularly those with amputations and serious disfigurements, claim to be able to earn up to several hundred thousand rupiah a day, ten times the minimum daily wage in the region. However, begging can be a physically demanding and dangerous occupation. There is significant risk of injury, particularly for those who move from place to place in carts.

In addition, beggars are often harassed by the police. Recently the city of Makassar enacted regulations forbidding begging, particularly in the streets. In response, with the support of Permata, a group of people with leprosy-related disabilities presented a petition to the local government assembly, which demanded that the government make itself responsible for the welfare of those prevented from earning a living by begging. So far, there has been no formal response to the petition.

One of the main goals of Permata is to eliminate discrimination against people with leprosy. One of the organization’s projects trains people with leprosy to interview each other and write up their personal experiences in autobiographical form, with the goal of publishing these stories to increase awareness of the issues that people with leprosy face. Mursalim’s story, published below, is one of more than fifty personal accounts that have been collated so far.

One of the most significant achievements in Jongaya is a self-care group, established by people with leprosy-related disabilities to support each other in practices that protect their health and well-being. One of the most effective interventions practiced by the members of leprosy group is the care and prevention of wounds to the feet. This is achieved by sitting together as a group...
to soak feet in water, then carefully scraping them with a rough stone and oiling them with any readily available vegetable oil.

In addition, the group established a micro-credit savings and loans system. Members make small, regular savings, and after a set period they are able to borrow money to establish, maintain, and expand small businesses. The cooperative was initially established with funds provided by the Netherlands Leprosy Relief organization. However, it is now self-sustaining, relying on repayments and savings to fund loans. Members have used funds, for example, to buy a computer and printer to rent and to buy a refrigerator to sell cold drinks.

Not all self-care groups in Indonesia have been as successful as the one in Jongaya. They often fail to reach the tipping point where enough people become convinced of the value of the system that it can be self-sustaining. Once members see their health improving, or they borrow money to set up a successful business, they usually become strong advocates and encourage others to join.

At Jongaya, many people with a similar affliction live in a single community. This works in favor of establishing a self-care group. It is harder to establish a successful group when people affected by leprosy do not live in close proximity to each other. In such cases, the cost and difficulty of travel may work against the success of a group.

Another issue is that participating in a self-care group means acknowledging, more or less publicly, that one has leprosy. Where there is stigma and denial, people may be reluctant to announce their condition in this way.
Andi Amin Reffi

For a long time I didn’t know I had leprosy. I didn’t want to know. Sometimes the kids at school saw the sores and the ugly white patches on my body. Sometimes they called me a leper. If they said it to my face, I’d smack them. My family knew there was something wrong but they never talked about it. My family is high-caste Bugis, from one of the royal families in the village. For an aristocratic family like mine, leprosy is terribly shameful. Some people believe lepers are cursed by God, others that it comes from black magic. It’s something unclean.

I was finally diagnosed in the late 1970s. Medical care wasn’t as good then as it is now. Back then, the drugs for treating leprosy were much less effective. A lot of strains of leprosy were resistant to the medicines they had, and not everyone responded well. The multi-drug therapy (MDT) that they have now is much better. If patients follow MDT for six months or a year, they can be completely cured. If people with leprosy are diagnosed early, they may not even suffer from complications. They can be completely cured and lead a normal life.

In the 1970s, I was prescribed Dapsone. I didn’t take it regularly. I only took it when I was feeling bad. That’s not the proper way to use it. You’ve got to go on taking it, even if you don’t feel sick. I didn’t know that at the time.

When I graduated from school, my parents used their influence to get me a job at the Governor’s office. Most people didn’t know that I was sick. I had a high school diploma, quite a good qualification back in the 1980s. Any sort of position at the Governor’s office, even a menial one, was very prestigious.

As part of the process of becoming a government employee, I had to have a medical examination. When the doctor examined me, he saw that I had leprosy. I was fired from my job immediately. Pretty soon, everybody knew why.

My family didn’t kick me out. I left by myself. Bugis people have a very strong sense of pride. I didn’t want to bring shame on my family. I just wanted to disappear from their lives and move away as far as I could so that I’d be somewhere where no one knew me.

The next few years of my life were a nightmare. It’s a blur now. I came to Makassar to hide in the big city. I did anything I could to survive. Sometimes I worked, sometimes I begged. Sometimes I stayed in rented rooms, or with friends, or even out on the streets. During that time, I didn’t have any contact with my family. I didn’t look after myself. I didn’t wash properly or change my clothes. I let myself get filthy. I thought I had a revolting disease, so I didn’t care what happened.

Eventually I came to the Jongaya Leprosy Settlement. No one is forced to live here, you know. It’s just much easier to live with other people who have suffered leprosy and who are used to dealing with it. Around here, there’s no need to be ashamed, even if you have amputations and other disfigurements. Around here, even people with serious leprosy-related disabilities can work or run a business.

On the main road here, there are small shops and food stalls run by people who have had leprosy. Of course they only sell to other people from the settlement! Normal, healthy people from the outside aren’t going to buy food from a leper, are they? It doesn’t matter if the person has been treated and isn’t infectious, and the food they are selling is wrapped in sterilized plastic: no one’s going to buy it. No one even wants to touch something that’s been handled by a leper. Sometimes shops refuse to serve someone who has had leprosy – they don’t even want to touch a leper’s money.

It’s different here. Back in the village, people who have had leprosy often feel that they have to hide themselves away. They wouldn’t be brave enough even to show
their faces in public. You can lead more of a normal life here. It’s a community. These days, the majority of people here don’t have leprosy. A lot of lepers have healthy partners and children. Out of the 2000 people in the settlement, about 600 have had leprosy. Everyone here is used to dealing with people who’ve had leprosy and have disabilities.

Back in 2006, we set up a self-care group. One of the big problems if you’ve had leprosy is keeping your hands and feet from getting damaged. Many of us have lost feeling in our hands and feet. If you stub your toe or tread on a nail, you may not even feel it. A lot of the women hurt their hands in the kitchen. If they aren’t careful, they can burn themselves and not even notice. If you get wounds like that, they can become infected. Your hands and feet can become gangrenous. That’s why so many people who’ve had leprosy have amputations.

Leprosy can make your skin dry out, too. When the skin on your feet dries out, it can get cracks, which can let the dirt in, and that can lead to infections. One of the best ways to prevent injuries to your feet is by soaking them in water. It’s really quite simple. You soak your feet in water for half an hour until the skin becomes softer, and then you rub the dry calluses with a stone. Then you apply coconut oil to keep the skin supple and to keep the moisture in. It sounds simple, but it really does work. The trouble is that people can’t be bothered. People say they are too busy working and they don’t have the time. Or they don’t really believe that it works.
So we set up a self-care group. We began in 2006, with just four people. Other people around the settlement began to see that it worked, so more and more people started joining. At one point, it went up to sixty people each week. Now it’s gone back down to about thirty. Some people do it at home now instead of coming to meetings. We meet every Monday. We sit together and soak our feet. People who’ve been in the group for a while explain how it works to those who have just joined. We just use water and soap and oil, but it works better than anything else. Some people had really bad wounds, so bad that the doctors said they were going to have to amputate. After they started soaking regularly, they got better.

At first, we just used buckets for soaking our feet. Last year we built special concrete troughs. Every week, we have an arisan, a kind of lottery. Each person who comes to the meeting puts in Rp 5000. Every week, taking it in turns, a different person gets to keep the pool of money. That person is responsible for buying the soap and the oil for everyone in the group. It doesn’t cost that much. It’s all made locally, stuff that you can buy around here.

Treating injuries and keeping them clean is vital. It can make the difference between losing a toe and keeping it. But avoiding injuries in the first place is just as important. That’s not always easy. Good shoes are important, but the type of work you do makes a big difference. With some types of work, it’s really difficult to watch your feet and your hands to make sure you aren’t damaging them. But we don’t have much choice. If people with leprosy have any sort of job, it’s likely to involve manual labor. It’s pretty hard to make sure you aren’t hurting yourself when you’re working in the fields. Jongaya is probably one of the better leper settlements in South Sulawesi. It’s close to the big city, so there are more opportunities. It’s much harder for people with leprosy in the rural areas. A lot of the men at Jongaya work in town as parking attendants. Many people with more serious disabilities beg, at least sometimes. But quite a few people here run a small business of some kind.

Last year, the self-care group received some funding from the Netherlands Leprosy Relief to set up a microfinance credit co-op. The co-op is open to anyone

Left
A patient in a hospital for people with leprosy-related conditions, keeping up appearances.

Opposite page
A man scraping calluses and dry skin from his feet.
who comes to the self-care group regularly. If you want to borrow money, there are a few extra conditions. It’s meant for people who are already running some kind of business, and the loan has to be used to develop or expand the business. There was one woman who sold drinks: she borrowed a few million to buy a fridge to keep them cool. Another woman borrowed some money to buy a computer and printer to rent out when people here need to print out a letter or document. And there’s a married couple who run a stall selling vegetables and basic foodstuffs. They ran into trouble, and borrowed money to restock and get started again. Everybody who joins the credit co-op makes a commitment to save a certain amount per month: if you make a commitment to save Rp 100,000 per month then you can borrow up to Rp 1,000,000, so long as you meet the other conditions. If you save more, then you can borrow more. Since the credit co-op started, more people have been coming to the self-care group: they can see that there are a lot of benefits for the people who join. They realize that working together benefits everyone.

Even so, there’s a limit to what we can do. It’s always going to be hard for people who have had leprosy, because of the way other people react to it. If people go on seeing it as a punishment or a curse or something disgusting instead of a medical condition, it’s always going to be hard for us to live in society. People need to realize that it’s just a medical condition and that we are just normal people like everyone else.
“I don’t beg. I just push myself along the streets in my cart. People wind down the windows of their cars and give me money. They feel sorry for me. I don’t ask for anything.”

Dalindring

I never come home with less than Rp 50,000. More often than not, I come back with Rp 100,000. I go out every day at seven in the morning and come back in time for the midday prayer. Pak Mursalim takes me into town on his motorbike every day. I pay him Rp 10,000 for his trouble.

My leg was amputated in 2002. It got twisted and dried, and got in the way. The doctors said I’d be better off without it, so they cut it off. Now I’ve got a false leg. I can walk with it. It hurts and I get tired, but I can walk with it. I don’t wear it when I go into town. People feel sorry for me because I have a leg missing. But otherwise I’m quite healthy. My hands and my foot are OK. I haven’t been to the hospital since the amputation. I haven’t seen a doctor or been to the community health center.

I try to stay healthy so I can go out onto the streets. Some guys go out the whole day, but they wear themselves out. I’ve got to pay for the rent on this house, and I’ve got to pay for food. The only help I get from the government is subsidized rice. I can get 25 kilograms a month for a bit more than Rp 20,000. But it’s terrible rice. It often has stones and insects in it.

I’ve got two children. The youngest is Jumardi. He’s in first class at junior high school. Yes, he’s healthy. I’ve been married four times. All my wives were healthy. I’ve just separated from my fourth wife. I used to give her all the money I took. She just spent it all, and not always on the right things. That’s why I haven’t saved any money. My wife spent it all.

There is a new government regulation that says you aren’t allowed to beg on the streets or at traffic lights, or in any public places. You can only beg outside mosques and churches.

I’ve never had trouble with the police or the Army. The police and soldiers sometimes give me money. The only people I’ve ever had trouble with are from the social welfare agency. They’ve taken me away a few times. They don’t do anything, they just drive me back to Jongaya and leave me here. They just tell me that I shouldn’t beg. I tell them I don’t beg, people just give me money. I don’t ask for it.

When the new law came in, we staged a demonstration. We went to the regional assembly to protest. They said we weren’t allowed to beg. We said we’d stop begging if they provided Rp 50,000 a day as a social security payment. We said we’d take a minimum of one million a month. They say we can’t beg, but they don’t offer any solution. What are we meant to do instead?

I found out about the demonstration from my other friends who go around the city in carts. We went to the assembly in a bus. We all paid our own fares. I didn’t meet any of the members of parliament. A few crippled lepers went in to meet them, but only the ones who had been to school. I never went to school.

What can I do if I can’t beg? I can’t work. I can’t work as a laborer with a missing leg. I can’t feel my foot or my hands. If I don’t look after myself, I mess them up. I don’t hurt my hands when I push myself around in my cart. I use a stick to pull myself along on the right side and push myself with my left leg. I have a shoe so I don’t hurt my foot.

If I had the capital, I’d set myself up in business. I could set up a business making bricks. But I don’t have the capital. I don’t go to the self-care group. My feet and hands have been clean for a long time. I wouldn’t have time to go to meetings in the mornings; that’s when I go into town.
Mursalim

When I was younger, I wanted to be a professor of electrical engineering. But when I finally graduated from junior high school, my mother enrolled me in the teacher’s vocational training high school. I was horribly disappointed about that, but I did what I was told. When I was in the first semester, I just happened to see a television program about leprosy and people affected by it. According to the program, one of the symptoms of leprosy is white or red patches of skin with no feeling. I couldn’t believe it: I had exactly the type of sores that were described on the television program. I was worried, so I told my mother. My mother was also alarmed and took me to the nearest community health center to get checked. The health worker told me that there was no way that it was leprosy, because no one else in my family had it. But after I graduated from school, I had another check-up. This time, the health center confirmed that I did indeed have leprosy. My mother was completely devastated by the news. But the health worker explained the implications of it to her so that she could understand. I went onto multi-drug therapy. Each month I was given the medicine I needed. I was supposed to keep on taking it for two years. After just one year, though, I felt a lot better, so I left home to look for work. I traveled to Southeast Sulawesi, where I got a job as a volunteer teacher at an Islamic religious school.

A year later, all the volunteer teachers were organizing their applications to join the public service. Just at that time, I started having serious adverse reactions to the medicine I was taking. I ended up going to Malaysia for treatment. I was in Malaysia for two years. But because of the cost of the treatment, my brother made me go back to Indonesia to get treatment here. In Indonesia, my condition got worse. In the end, I was completely paralyzed. My leg became twisted and bent, and I couldn’t straighten it at all. The fingers on my hands began to dry and shrivel, becoming clawed. I went to see a dukun, a traditional healer. He told me to throw away my medicine. He told me that the medicine was making my condition worse.

With my condition getting worse, people in the community began avoiding me. Before then, they hadn’t really known that I had leprosy, so I was still allowed to live at home in the community. When people found out that I had leprosy, everyone avoided me. They didn’t want me to live there anymore. My brother came with me when I left home. I went around trying to find someone to take me in, but word had gotten around that I had leprosy, and no one would take me in. I felt like a rotten fish being passed from buyer to buyer. I went to a friend from school who didn’t know that I had leprosy, and he let me stay.

That afternoon, though, a health worker came to the house and told my friend that I had leprosy. I knew that I was going to get kicked out again, and I was right. The same day my friend told me to get out. I was completely devastated and had no idea what I should do. One of my brothers patiently came out in the middle of the night and helped find another place where I could stay. I know how difficult and confusing it must have been for my family, too. Try to imagine how it would feel if it happened to your brother. But they didn’t want to abandon me. They took me round from place to place, looking for someone kind enough to take me in. No one would take me. It was just too much, so I flopped down and bawled my eyes out. I looked at my two brothers and said, “Just cut me loose. Let me go.” When my elder brother heard me, he hugged me and told me that I had to be patient. He said that if no one took me in, he’d stay with me in the forest while I took medicine and got better.

After he said that, both my brothers sat down and cried. I couldn’t help asking
where we were going to go next. My brother answered that God would guide us somehow. Just after that, a stranger came up and greeted us and asked us what was wrong. We told him, and he told my brother to bring me to his house. I ended up staying there. He looked after me like I was his own child. He never complained about the trouble I was causing. I’ll always be grateful to that man. I got well enough that I could make my way to the Daya Makassar Leprosy Hospital. In the leprosy hospital, they made sure I took the medicine properly. I found a new life there. The hospital was completely different from outside: no one treated me badly or unfairly. They gave me excellent medical treatment, completely unlike the treatment I’d had before. I stayed in the hospital for eight months. By the end, I was almost completely well again.

I had no idea what to do or where to go after I left the hospital. I thought people would still try to avoid me, but they couldn’t even tell that I’d had leprosy. I wanted to go back to my village, but I didn’t have anywhere to go there. I didn’t know how to support myself in Makassar. I just wandered around at a complete loss, not knowing what to do. I knew that I had to find some work in order to survive. I looked around at the people working in the street. I saw people working as scavengers, parking attendants, and so on. In the end, I decided to try to earn money as a parking attendant. I waited until one parking attendant went home, and I just filled in for him before anyone came to replace him. Of course, I didn’t get much, but I had enough to eat.

Even though I’m accepted by the community now, sometimes I still feel sad when I see how people treat lepers and people with leprosy-related disabilities. Maybe they ended up that way because they didn’t get treatment soon enough. That’s why people end up with disabilities. Even so, once they are treated, they are completely cured of leprosy, just the way I and the luckier ones are.

I wish that people in the community wouldn’t feel such revulsion and fear when they meet lepers. If they have been treated, they aren’t infectious anymore. Almost everyone has a natural immunity to leprosy. It’s only people with a very weak immune system who are vulnerable. Lots of children are born to mothers who have had leprosy and live with her until they grow up, but they aren’t infected! There are lots of people with leprosy who have a healthy spouse. And their children and grandchildren are healthy. Just to give you an example, the brother whom I talked about before, who looked after me when I was sick and cleaned me up and hugged me because he was so sad to see the state I was in – he’s still healthy. There’s no reason to be afraid. I looked after a child, like a foster father while he grew up, from when he went to primary school until he graduated. He’s married now. He slept in my room and ate with me, and he’s still healthy.

I’d just like to say to everyone who reads my story here, I hope you have learned a little bit about leprosy, and if you meet someone with the symptoms that I described earlier, please encourage them to go to the nearest community health center. If you have the symptoms yourself, please don’t be embarrassed about going to the doctor. The medicine is free! Your condition will deteriorate if you don’t get treatment. And to the government, I’d like to say that we would be really, really grateful if you would help us make people more aware of the real nature of our condition, so they will know that we are really just like them. Empower us to do the best we can. And for those of our friends who are in such bad condition that they can’t look after themselves anymore, give them a pension or an allowance of some kind. Prove that Indonesia can be magnanimous and generous.
Mading wears glasses to protect his remaining eye.

Mading

I wear glasses to protect my eye. I’ve only got one eye, and it doesn’t close properly. I’ve got to keep the dust out. I can’t rub it, or I’ll lose that one, too. I don’t have any feeling in my arms, all the way up to my elbows. I don’t have any feeling in my legs from my knees down.

I sit outside the Toko Agung shop in the afternoons. I don’t get that much money. At the most, people give me Rp 30,000 per day. The people with amputations make more than I do. You make more if you push yourself around in a cart than if you just sit still in one spot. But if you go from place to place, you’re more likely to hurt your feet and hands. If you sit still, there isn’t so much risk. I don’t wear my glasses when I’m sitting outside the shop. People think I’m rich if I wear glasses. So I take them off and keep them in my pocket.

It’s against the law to beg in the streets now. It’s OK in my spot, as that’s on private land. I’ve been sitting there in the afternoons for four years now. The owner of the shop says it’s OK if there’s just one person there, but he doesn’t want a lot of other beggars. The security people are OK, they don’t give me any trouble, but they shoo away anyone else.

I’ve had some trouble with the social welfare people. They saw me talking to you today, and they came up and asked me what we were talking about. They’ve taken me away once or twice, but they just take me to their office and then back here to Jongaya. I still go out the next day.

I don’t like begging, but what else can I do? I’ve got to pay the rent on my house and I’ve got to look after my wife. If the government wants us to stop begging, they should provide us with some security.

I go to the self-care group in the mornings. They talk to me about protecting my eye. I’ve never borrowed money from the credit co-op there, though. I’m 67 years old. I’d like to set up a business, but it isn’t that easy. I’m not sure what kind of business I’d like to run. It’s hard to set up a business when you are getting old and you’ve got disabilities like mine.
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 meetings and provided all sorts of other assistance. A partial list of these people includes Marjorie, Mateo, Marwan and all the staff of Handicap International in Banda Aceh and Takengon; Rico Sinaga from the Puskesmas (Community Health Center) in Cikini, Jakarta; Imam B. Prasodjo and the staff of Yayasan Nurani Dunia; the members of the band Cispleng and the young guys and women who hang out in Proklamasi; Kamala Chandrakirana, sociologist, author and former Chairwoman of Komnas Perempuan (the National Commission on Violence against Women); Kadar Wusana and Nani Zulimarni of PEKKA (the Women Headed Household Empowerment Program) in Jakarta and the PEKKA field facilitator in Lingsar, West Lombok, Sitti Zamrani Alauith; Fenny Purnawan, writer, editor and mother of Gana, Smita, Anggita and Oorvi. Agas Bene of the Dinas Kesehatan (Health Agency) in Belu, West Timor; Maria K’lau, an outstandingly dedicated midwife in Belu; Antonia Godelpia Lau, the manager of the Panti Rawat Gizi and all the doctors, midwives, staff and workers at the Puskesmas in Belu; Anne Vincent, Fajar, and Anton Susanto of UNICEF in Jakarta; Neldan Djakababa and Vitria Lazzarini, psychologists from Yayasan Pulih; Piet Pattiwaelapia of the Maluku Refugees’ Coalition (Koalisi Pengungsi Maluku); Nelke Huliselan, a community worker in Ambon; Ennra Diah, a plastic surgeon; Julia Suryakusuma; Richard Oh, novelist and crewcut; Rebekka Harsono, an activist from LADI (the Indonesian Anti-Discrimination League); Pephy Nengsi Golo Yosep and Adi Yosep, activists for the rights of people affected by leprosy in Jongaya, Makassar; Kerstin Beise of Netherlands Leprosy Relief (NLR); Dede Oetomo and friends from GAYa Nusantara (a gay and transgendered rights organization in Surabaya); Irma Soebechi and friends from Perwakakos (transgendered rights organization); Nig and friends from US Community (a gay and lesbian rights organization in Surabaya); Ayi Na, previously at UNICEF in Mangkowari, Papua; the indefatigable Sister Zita Kuswati at Yayasan Saint Augustine in Sorong, Papua; Connie de Vos, a linguist and specialist in sign languages; Thomas J. Conners, a linguist at Max-Planck-Gesellschaft; Josh Estey, photographer and crewcut; Dian Estey, journalist; Maya Satrini, community worker and friend of the sex workers in Singkawang; Rina, Dewi, Adhe and Yuyun and other sex workers in Jakarta; psychologist Jeanette Murad of the University of Indonesia; Alexander Sriewigjono, consultant; Mustamin, of the Bajau community in Mola Selatan, Wakatobi; the Forkani environmental protection group on Palau Dupa; Veda and Rili Djohani of The Nature Conservancy; Ani Himawati in Jogja; Ayu Sastrosusilo, all of the people from Humana, an organization advocating for the rights of street children in Jogja; Muhammad Zamzam Fauzanafi, visual anthropologist; Mbak Diaj, an activist filmmaker, and all the other people at Kampung Halaman in Jogja.
The project would not have been possible without the support of Sujana Royat, the far-sighted Deputy Minister for Poverty Alleviation in the Department of Social Welfare. In addition to being a driving force behind the Indonesian government’s involvement in the PNPM Mandiri program, he has worked tirelessly to raise the profile of Indonesia’s invisible people and to include them in the development process though his active support of PEKKA and a number of the people, groups, communities, and programs described in this book.

Nor would the publication of Invisible People have been possible without the patience, tenacity, and kindness of Threesia Siregar, of the World Bank’s PNPM Support Facility. The support of Victor Bottini, Ela Hasanah, Sentot Surya Satria, Inge Tan, Lisa Warouw, Rumati Aritonang, Nancy Armando Syariff, Juliana Wilson and all other staff at the PNPM Support Facility. In addition to providing his introduction, Scott Guggenheim, of AUSAID, kept the project alive with his wisdom, and sense of humor, editing the English language text, and making sensible suggestions throughout the project. Erick Sulistio used his extraordinary talents as a designer to transform the words and images in this book into a visually impressive final product. Sila Wikaningtyas worked long and hard to produce profound and sensitive Indonesian translations of the text, which was originally written in English, as well as a number of personal accounts written by the subjects. Jamie James played a valuable role tweaking, proofing, and editing the final English-language text, while Dorothea Rosa Herliany performed a similar role with the Indonesian-language text. John McGlynn, of the Lontar Foundation, provided excellent advice regarding the publication and distribution of the book.

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], 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 Srimayani (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. 136); Megi Budi (p. 137, p. 139); Rifky (p. 138); and Reza (p. 148, p. 149).