



# INVISIBLE PEOPLE

POVERTY AND EMPOWERMENT  
IN INDONESIA

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

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Banda Aceh and Takengon, Aceh

## DISABILITY: ACCESS AND OPPORTUNITY

On December 26, 2004, the deadliest tsunami in recorded history killed almost a quarter of a million people in thirteen countries in less than thirty minutes. More than half of these people died in Aceh, an Indonesian province that had for decades been isolated by a violent and ugly conflict between the separatist movement and the Indonesian armed forces. More than half a million people's homes were destroyed by the waves. Entire communities were wiped off the map.

The destruction of entire towns and villages and the displacement of hundreds of thousands of people were followed by the most ambitious reconstruction operation in history. With mottoes such as "Build Back Better," and with access to huge amounts of funding, many of the agencies and organizations involved in reconstruction engaged in varying forms of social engineering. Organizations such as Handicap International lobbied hard for public facilities such as meeting places, schools, and mosques to be rebuilt to allow universal access. This organization pushed for buildings to be designed to meet the needs of "people of all ages, sizes, and abilities." This included the disabled.

According to the 2000 National Survey, the number of people with disabilities living throughout Indonesia was almost 1.5 million, less than 1% of the total population. This compares to a World Health Organization estimate that around the world, approximately 10% of the world's population is significantly disabled. Throughout Indonesia, many factors contribute to this systematic under-reporting of the number of disabled people. Many disabled people are simply not visible. They are often excluded from the everyday life of their communities, they are unemployed, they remain at home, or they are entirely without identity documents and are not registered with government authorities.

In Indonesia, people with disabilities are often excluded from full participation in society by lack of access. People with physical disabilities may have difficulty attending school. Without educational qualifications, they are even less likely to be able to find work. Access to offices, factories, and other workplaces may also be limited. Because people with disabilities can't work when no accommodations are made to their needs, they become poor.

People see the poor in wheelchairs or on crutches, and assume that they are poor because they can't do anything useful. If they can't do anything useful, this line of reasoning goes, then it would be a waste of resources to create special facilities for them. Yet if people can't leave their homes, they can't use public facilities. If people in wheelchairs can't go to parks, shopping centers, or hotels because they don't have ramps, for example, then they won't be seen in public. If they aren't visible in public, most people don't see them. If people don't see people with disabilities, they don't merely assume that they can't do anything useful: they don't see them at all.

The concept of universal access is based on the belief that when appropriate accommodations are made for people with disabilities, the limits on their activities are eliminated or reduced. When the limits on people's activities are eliminated or reduced, they are no longer disabled, because they can participate in a full range of activities in the community in which they live.

Some of the major reconstruction efforts in Aceh paid attention to the plea by such organizations for universal access. UNICEF rebuilt 300 schools and repaired another 200 damaged schools throughout Aceh. These schools were built according to universal design principles and were intended to be accessible for children with disabilities. The United Nations Development Program promised

**When disabled people have facilities that allow them to take part in the life of the community, they cease to be disabled.**

to facilitate the construction of 400 houses specifically designed to be accessible for people with disabilities.

A few highly visible public buildings, such as the Oman Mosque and the Taman Sari public park in Banda Aceh, were also designed and built to allow universal access. Handicap International involved architects and architecture students from local universities in the design and reconstruction of these buildings. Through their participation in these projects, they became aware that simple adaptations in building design and construction could improve access for people with a range of disabilities.

It is not enough to build accessible buildings and other facilities. Often, people who have been excluded from participation need special care, instruction, and guidance in order to make use of available facilities and to achieve their full potential. For this reason, Handicap International and the small handful of organizations that work with people with physical disabilities in Aceh sponsor the donation of wheelchairs and prosthetic limbs in certain districts to people who need them.

Handicap International is also involved in training and economic empowerment programs. These often dramatically change the lives of those receiving training and guidance. By helping people with disabilities to achieve their full potential, these programs also change the way the rest of the society views them. When enough people become aware that the disabled can make significant contributions, then the community may be prepared to devote the resources required to make it possible for them to make these contributions.



## Nurbaidarmi

I'm a paraplegic. I've got no idea how I became this way. When I was at school, I used to love sports. I was the strongest girl in the class. I used to love running. I was always in the school sport competitions. There were times when I fell and hurt myself, but I don't remember the fall that paralyzed me. When I was fourteen, I suddenly had excruciating pain in my back. Then I had a terrible fever. Suddenly, I couldn't move my legs. I couldn't even feel them. It felt like they were dead.

My father took me to the hospital in Banda Aceh. I stayed there for seven days. The doctors didn't know why I wasn't able to move. They sent me to Medan, where the hospitals are better. I was in hospital in Medan for fifteen days. When I was in the hospital, I heard one of the nurses say "She's such a pretty girl. It's too bad she's paralyzed." That was how I found out that I'd broken my spine.

I remember shouting at my father and telling him what the nurse had said. I remember telling him it wasn't true. And then I didn't want to talk to anyone. I couldn't bear it. I remember my father telling me that he'd get me a wheelchair. I didn't want it. I hated my father even for suggesting it.

I just lie on a mattress in my room. I have no control over my bladder. I can't stop myself urinating. I have to change my clothes ten times a day or even more. I've hardly got any meat left on my legs, so my bones always rub straight against the mattress. I get sores all over my body. They often get infected. Sometimes I get sick from the infections.

The most disgusting thing is the rats and insects. They nibble and gnaw on my toes. I can't feel them doing it. I wrap my feet up with cloth so that the rats can't

**"I haven't taught at the school for the past three months. The village authorities began repairing the road outside my house. They put stones there to stop the road being washed away. It means that I can't push myself to school in my wheelchair anymore."**



get to them, but they chew their way through the cloth. I have to always watch my feet and protect them.

My father told me about a special school in Banda Aceh. It was a school for people with disabilities, but I wasn't interested. I was ashamed of urinating uncontrollably in front of other people. I didn't know that loss of bladder control was a problem that all paraplegics have. No one ever told me that. I thought it was just me. So I didn't want to go to school. I just stayed in my room.

Most of the time, I listened to the radio. I liked reading, too. I read anything that I could get my hands on, magazines, newspapers, books. I liked reading about people in wheelchairs in the paper. I didn't have any disabled friends and I never went out of the house, so that was how I learned about how other people like me coped.

I didn't use a wheelchair for years. As time went by, I began to accept my situation. In 1990, I let my father buy me a wheelchair. There was no path at the front of the house, so I couldn't go anywhere. At least I could sit outside. Sometimes friends or family came to visit me. I started to enjoy being with people again. I started to draw, too. I had plenty of time. I just taught myself how. The kids around here used to watch me drawing and they always asked me to give them drawings. That was how I filled my time.

Things changed after the tsunami. A lot of foreign NGOs and aid organizations came to Banda Aceh after the tsunami. My brother was working in town. He met someone who told him about Handicap International. They had a program to provide wheelchairs to people who needed them. I'll be honest with you: I was very suspicious at first. I'm Acehnese. I'm a Muslim. I didn't want to ask the foreign NGOs for anything. I thought they might want me to become a Christian if they gave me something. But my brother encouraged me.

Some people from the organization came out to meet me. They asked me a lot of questions. They asked me what I wanted to do with my life. They asked me what I wanted to do after I got my wheelchair. They came out to my home more than six times to interview me. My mother asked me: Why don't they just give you a wheelchair? Why do they keep asking all these silly questions?



#### Right

A self-portrait by Nurbaidarmi.

#### Following pages

Prior to the "repairs" to the road in front of her house, Nurbaidarmi was able to work in a nearby school.









But the people from Handicap International wanted to know about my house and how I lived there. They offered me a grant to make my house more accessible. They asked me if I needed to have better access to the bathroom. They suggested making the floor flat and widening the door. But I told them that even more important than the bathroom, I wanted somewhere where I could wash my own clothes.

My mother is getting old. She was getting too old to keep on washing the clothes that I'd urinated on. Once she fell over while she was carrying them. I couldn't do anything to help her get up. I was so ashamed. I said if there was money available to reconstruct my house, I wanted to be able to wash my own clothes. The people asked me to draw a plan to show what I wanted. They suggested a few changes to make my plans more practical. They built a low basin outside my room. They also built a paved path so that I could get my chair to the road in front of my house.

The people from the organization told me that if I had a wheelchair, I should think about what I wanted to do after I got it. They asked me if I'd thought about getting a job. I laughed and told them that no one would employ an unqualified woman in a wheelchair. They told me just to imagine that I could do anything I wanted. I didn't take it seriously. I told them I liked playing with children. I liked drawing. I said I'd like to be a teacher.

They told me about an early child care and education course being held by UNESCO, a twenty-five-day course. I still didn't think I could do it. I told them that I was scared that I'd urinate in front of the other students. They told me about diapers for paraplegics. They said if that was the only problem, they'd get the diapers for me.

I was the only disabled person in the course.

There is a play group in the village about a hundred meters from my house. When I finished the course, I started working there as a volunteer teacher. I don't get a salary. Sometimes I get cash gifts from the school authority or from parents. The kids like me. I draw pictures and write stories to go with them. I read the stories to the children. I've never published them. I just give them to the kids in my neighborhood. They are always asking me for them. But I haven't taught at the school for the past three months. The village authorities began repairing the road outside my house. They put stones there to stop the road being washed away. It means that I can't push myself to school in my wheelchair anymore.

Could they have made a special path along the road for me? *[Laughs]* I'd be embarrassed to ask for something like that. They'd have to go to all that trouble just for me. No, you're right, it wouldn't have cost much. They could have just left a strip next to the road without stones.

I've never been to any village planning meetings. Someone would have to carry me. I'd be embarrassed to go and talk to the village head and ask him for a special favor. The head of the playschool and the other teachers didn't realize. I don't think they could have done anything. Anyway, a lot of the kids still come to visit me at my house. I still do my drawings and tell them stories.

## Ella

**“Now when I fall over, I need someone to help me stand up again. I can’t get up by myself. I’m not embarrassed about that anymore. I believe in myself. I keep on trying.”**

When I went to primary school, I couldn’t walk. I could only crawl on my knees. My little brother used to carry me to school on his back and leave me at the classroom. Then I would drag myself along the ground to my desk. Most of the kids at school were OK. Some of them didn’t want to play with me because I was disabled. Some of them were nasty to me. Some of them pushed me from behind after I’d dragged myself up onto my chair, to make me fall off. I never reacted or got angry. I just pulled myself back onto my chair as though nothing had happened.

When I was at primary school, I had very high ambitions. I wanted to be a doctor. But after I finished primary school, my father wouldn’t let me go to high school. He said he was worried that I’d be hit by a car on the road on the way to school. He told me that he was scared I’d hurt myself. I cried and cried, but I couldn’t change his mind.

After I finished school, the social welfare department arranged a sewing course for me, with a group of other disabled people. We were all mixed in together: there were some deaf people, some blind people, and one or two with Down’s syndrome. I finished the course, but it’s very hard to get work with those skills. I can’t work sewing all day. With my condition, my hands hurt too much. It’s too painful.

Ella has muscular dystrophy, a degenerative condition that weakens the muscles.



In 2006, I started doing physiotherapy at the local community health center. Some physiotherapists from Handicap International were working there. I went to the center once a week for five months to do the training. They made me stand up holding a rail. At first my brother used to carry me to the community health center, but then they said I had to get there by myself, even if I had to crawl. After a few months, I could walk with crutches. By the end, I could walk on my own. When I finished, they asked me to walk in front of some doctors. I wasn't shy about it. I was proud that I could walk without crutches.

When I finished my physiotherapy, the people at the program told me that there were some funds available to help me earn a living. They gave me a choice. They said they could send me on a course to finish school or they could provide some capital so I could set up a small kiosk selling dry goods at the front of my house.

I wanted to set up a kiosk. I figured that even if I finished school, it would be very difficult to get a job. So I decided to set up the kiosk. They gave me Rp 775,000. I don't have to pay it back, but they make me keep records of my sales and income. They come around to check to see if I'm still in business. You can see the book here! Sometimes I take in Rp 300,000 in a day, sometimes I only take in Rp 100,000.

Elta earns about Rp 20,000 per day selling non-perishable goods to neighbors. She is the major breadwinner in the family.





Most people with Ella's form of muscular dystrophy die in their late teens or early twenties. At 23, Ella is already considered to be a long-term survivor. Ella is seen here with her family.

I bought that big box of noodles for Rp 28,000. It contains thirty packs of Indomie and I sell them for Rp 1000 each, so I make Rp 2000 if I sell the whole box. It isn't very profitable, but I make enough to buy groceries for the family. Maybe I make about Rp 20,000 per day. My father doesn't work anymore, so most of the family's income comes from my kiosk. The only thing I can't do is go down to the village to restock. My father helps me do that.

One of my biggest problems is that people often want to buy on credit. That means I don't have the cash to restock. Mostly people pay their debts, but sometimes it takes a long time. And now prices are going up. If I had a bit more capital, I'd be able to make sure that I was always stocked up. I'd like to expand the kiosk a bit. I don't want to sell cooked food, it's too risky. If you don't sell it all, you can't keep it for the next day. But I'd like to sell rice, flour, and other foodstuffs. I'd like to pull this wall out to open up the kiosk and have more space.

I'm still healthy. My muscles are wasting away, but if I keep active, I'll stay healthy. I do have some problems. A year or two ago, if I fell over, I could stand up by myself. Now when I fall over, I need someone to help me stand up again. I can't get up by myself. I'm not embarrassed about that anymore. I believe in myself. I keep on trying.

## M. Jusup Ariga

I was cutting wood with a circular saw, and the blade broke. It went flying off and hit me in the leg, below the knee. It was severed almost all the way through. It was just hanging on by a piece of skin. Too bad it happened on a Sunday. There were no specialists at the hospital on a Sunday. If I'd been in Medan, perhaps they could have saved it.

The doctor wanted to cut above the knee. I told him he was an idiot. I asked him where he went to medical school. I told him to leave my knee alone and cut below. I'm just a mechanic, but even I knew that I wouldn't be able to walk again if he cut above the knee. So he did it the right way. You can't trust doctors here. Half the time they don't know what they are doing.

After the wound healed, the people at the community health center told me that I could go to Banda Aceh to have a prosthetic leg fitted. I was there for three days while they fitted it. The physiotherapist gave me some exercises to do. When I got back to Takengon, I kept on doing them. The physiotherapist here came to my house several times to make sure I was doing OK. My wife works in the administration of the local school. She's a civil servant, so I was eligible for the health insurance scheme for civil servants and their families. I had to pay for my own transportation and accommodations, but the prosthetic limb, the treatment, and the medicine were all free.

At first the stump rubbed raw and it hurt, but I kept on going. After a while, it toughened up. I can do almost anything that anyone else can do. I still work as a laborer on building sites. The only thing I can't do is climb up scaffolding or onto a roof. But I'm still strong. I still work as a driver, too. I do a lot of different jobs.

If I had the money, I'd like to set up a business as a mechanic. Our house is on the main road, so I could set it up right out front. I just don't have the capital. Sometimes I work at another mechanic's. If I had the money to buy the tools, I'd set up my own business. It would be good for when I get older.

There's another guy in Takengon with a missing leg. He doesn't wear a prosthetic limb. He uses crutches. Maybe he doesn't want to wear the leg. Maybe he thinks it's easier to beg than to work. Maybe people feel sorry for him because he's missing a leg. I'm not like that. I want to go on being independent.

**"I don't feel disabled. You can't tell I'm wearing a false leg just by looking at me. I can do almost everything I could before the accident."**



With his prosthetic leg, Jusup is able to drive a car, stand and walk freely, and perform many kinds of work.





## Samsuar

I fell out of a coconut tree ten years ago. I was going to get married the next day. After I fell from the tree, the girl's family put the wedding off. The woman who was going to be my wife kept on visiting me for the next two years, but I didn't ever get better. In the end, she stopped coming around.

I live in a shed next to the mechanic's workshop. My nephew rents space for a kiosk on the other side of the workshop. He built this shed for me to sleep in, and gives me scraps of food.

I have a wheelchair. It's my third chair. I got it through the hospital. When I went to the hospital, I had a letter from the village head that said I was poor and couldn't afford treatment, so I didn't have to pay for it. If you have a letter, they give you free medicine. They just have two types of medicine. There's one if you have a headache and one if you have a stomachache. It's better to buy your own medicine.

I can get out of my shed by myself. I can get my wheelchair over those rocks. In the afternoon, I go to the bus terminal. I don't beg, but sometimes people give me money. Sometimes I just find money that people have dropped in the street.

Before I had this chair, I used to drag myself along the ground using sticks. You see the wounds on my feet? That's because I can't feel anything in my legs. Sometimes I cut myself, and I don't feel it until I see myself bleeding. Sometimes my feet get blistered from the hot road. I've had the sores on this foot for years. Sometimes they get better, but they never completely heal. They are getting better now that I have my wheelchair.

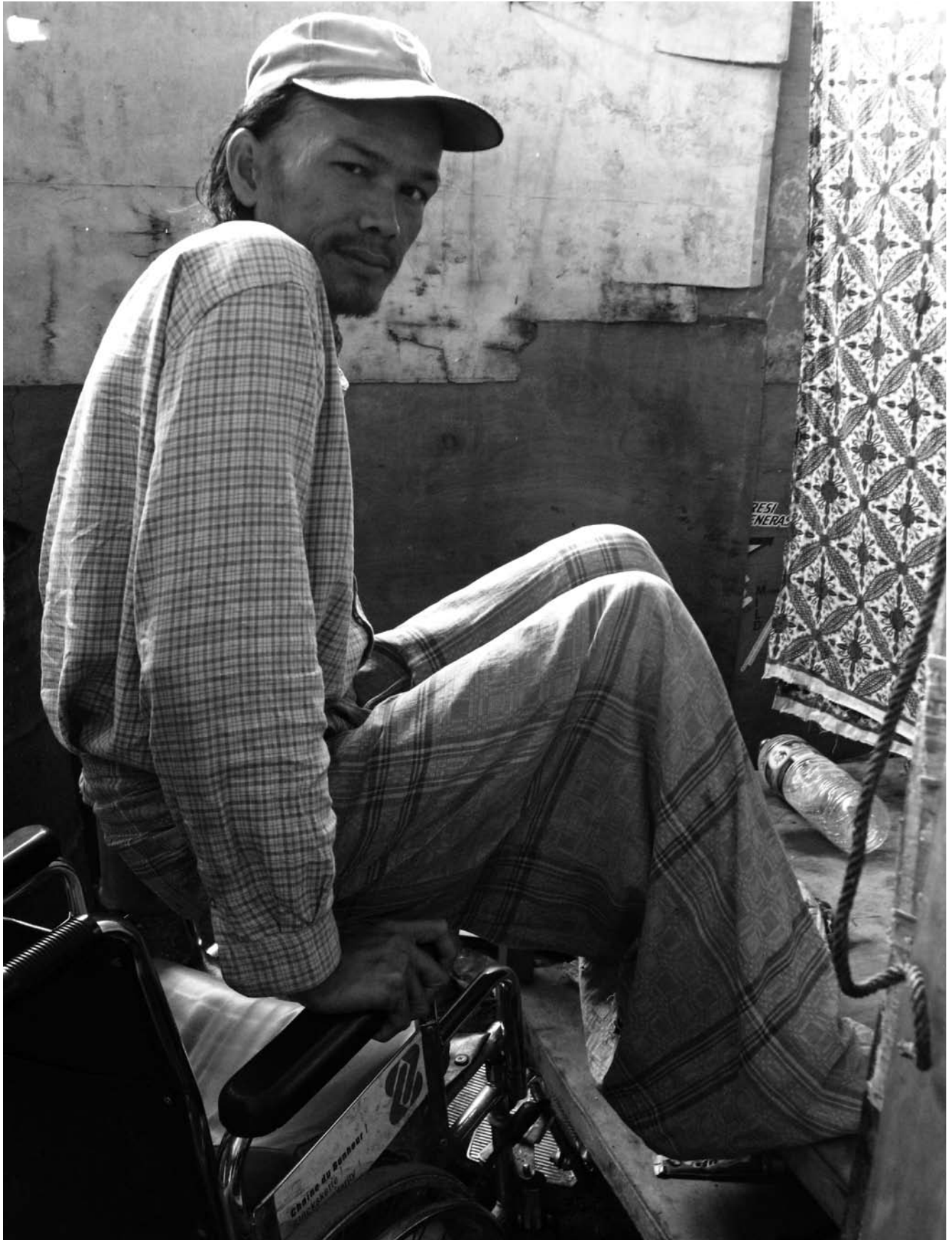
**"You see the wounds on my feet?**

**Sometimes my feet get blistered from the hot road. I've had sores on this foot for years. Sometimes they get better, but they never completely heal."**

### **Below**

Samsuar lives in a reconstructed packing case on vacant land.





## 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).

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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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