

# Pasung: The Agony of Chains

## Photographs by Andrea Star Reese Text by Loretta Oleck & Andrea Star Reese

"The most violent element in society is ignorance."

-- Emma Goldma

"So many people are shut up tight inside themselves like boxes, yet they would open up, unfolding quite wonderfully, if only you were interested in them."

— Sylvia Plath

Thousands of mentally ill people are locked away in rooms, cells, cages, or animal sheds, restrained in chains or wooden stocks. Many are left naked, hungry, with no ability to wash, and vulnerable to malnutrition, assault, and rape. In Indonesia, this form of abusive "treatment" is called pasung. It is often imposed on individuals of any age who exhibit behaviors, attitudes, or emotional expression that are atypical. Pasung can be enforced for weeks, months, or even years. Although pasung has been banned by the government since 1977, it continues to be the widespread traditional response to mental disorders throughout Indonesia. Yeni Rosa Damayanti, head of Perhimpunan Jiwa Sehat-Indonesian Mental Health Association, in Jakarta, says, "You can throw a stone anywhere in Java and you will hit someone in pasung. That's how prevalent it is." She also states, "People with a mental health problem are at the bottom of the chain/cycle of violence that results in human rights abuses. The difference between having access to service and no access at all is to be forced to live in hell. It is between living and not living."



Agus sings in his cage, his hands moving in an intricate dance. His feet are in a gutter filled with water that he uses when he is thirsty.



Although pasung can occur at an institution, shelter, or a religious run center, it often takes place at home. It is imposed by family members who cannot afford a higher level of care, have no support system, cannot or do not know how to access services, fear medications, worry about addiction, or most significantly, want to avoid the stigma linked to a diagnosis of mental illness. Most commonly, they feel pasung is a necessary step to protect the family, community as well as the nonconforming individual.

One young man with psychosocial disabilities named Ekram was locked in a shed by his family. They engaged in pasung in order to keep him separated from the rest of the family as well as the village. They passed food to him through a small hole. Ekram, like so many others living in similar conditions, has been living without rights, and forced against his will into squalor, isolation, restraint, and abuse.



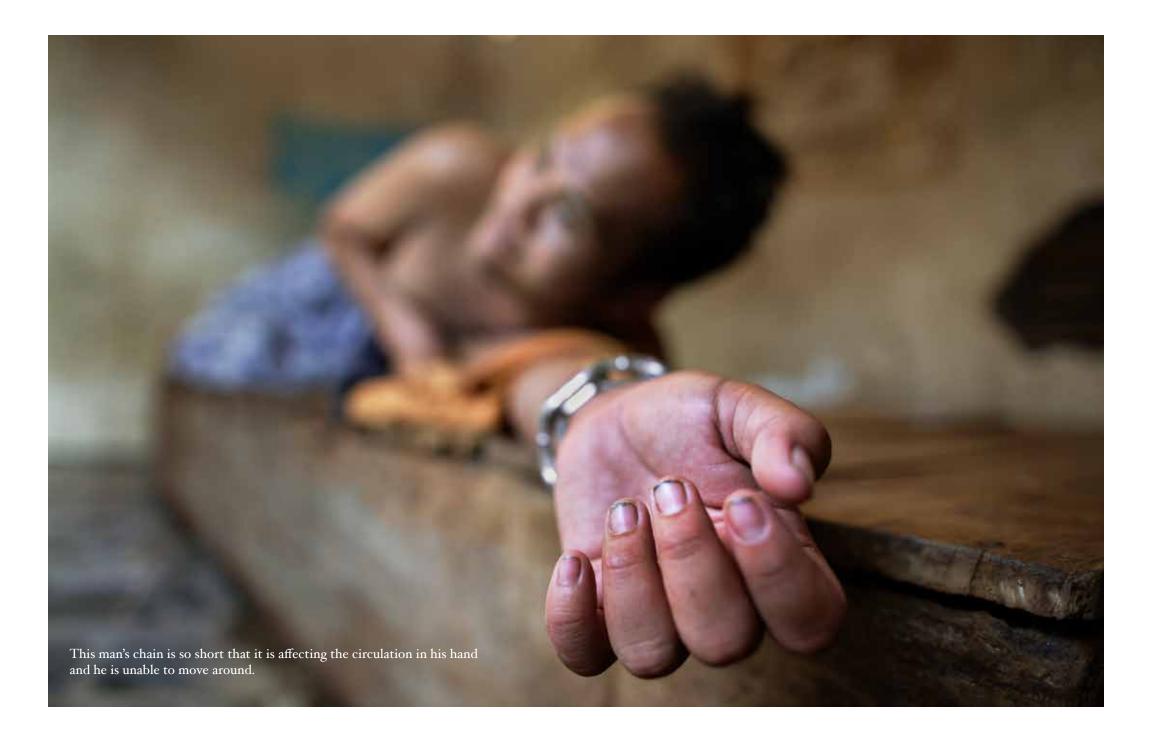
Wawan, 49, has been living in a chicken coop alongside his family home for a year. He cannot stand. Wawan's family does not know how to help him.



Saepudin lived shackled in stocks for nine years in a back room in his family's home in Cianjur in West Java. When he was released, his legs had atrophied from disuse.

1. "Indonesia's Mentally Ill, Shackled and Sexually Abused in Care Centers," *Independent*, March 21, 2016, http://www.independent.co.uk/news/world/asia/Indonesia-mentally-ill-shackled-and-sexually-abused-in-care-centres-A6943236.html





Indonesia, the fourth largest country in the world, consisting of a population of 250 million, has over 19 million people with psychosocial disabilities. A psychosocial disability is an internationally recognized term under the "United Nations Convention on the Rights of Persons with Disabilities," used to describe the experience of people with impairments and participation restrictions related to mental health conditions. The Convention on the Rights of Persons with Disabilities (CRPD) was passed by the General Assembly of the United Nations in December 2006. By February 2013, it had been signed by 155 countries and ratified by 127. It sets out fundamental rights that citizens with a disability should attain in a fair society. It is one of the nine core human rights treaties of the United Nations. The overall purpose, stated in Article 1, is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."<sup>2</sup>



The island nation of Indonesia.

Rafi is a 29-year-old man with a mental health condition who was involuntarily placed at Yayasan Galuh Rehabilitation Center in Bekasi. He is one of 18,800 people currently living in pasung. According to The Human Rights Watch (2016), "57,000 people with real or perceived psychosocial disabilities (mental health conditions) in Indonesia have been in pasung (shackled or locked up in confined spaces) at least once in their lives."3 Galuh, where Rafi was being held, has undergone a transformation over the past five years. In the past, individuals were kept in a large caged space in the open air. Men and women were living separated by a wire fence wall. Now, these spaces have disappeared, and a new open-air structure was built where residents are confined in smaller rooms and there are staff desks on each of the two floors. Some of the residents are able to go outside into the surrounding grounds. Some wander about as helpers. Even with these improvements, however, due to its cage-like structure, privacy remains an issue. Chains have been used on "difficult patients," even though isolation rooms are available. Galuh is not considered to be a hospital but rather a large shelter where the police bring people who need hospitalization. Galuh is located in a more convenient location than taking individuals to a mental hospital a few hours away in Jakarta. Nevertheless, the actual mental hospitals offer better living conditions and treatment since there are usually a few psychiatrists, nurses, and doctors on staff.

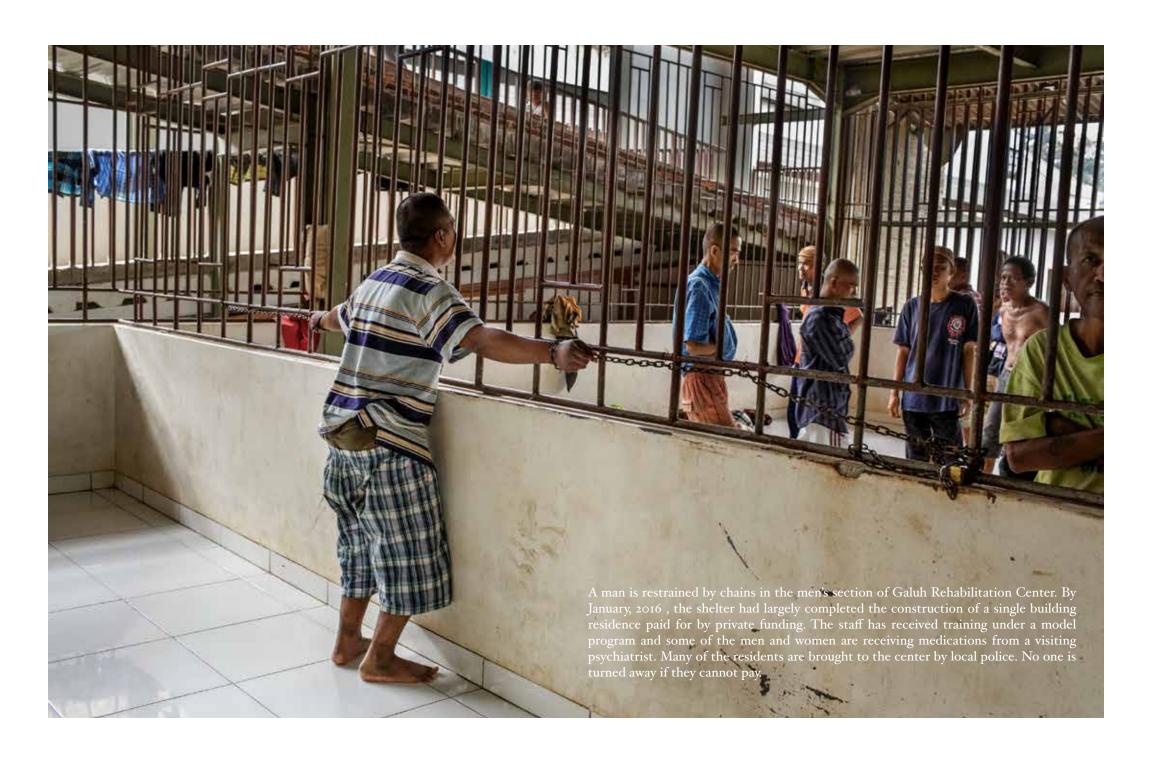
Rafi, who was living at Galuh, said, "I used to be tied up at home with a plastic rope. My heart broke when they chained me....I was chained when I first came [to Galuh]. I get chained often—at least 10 times since I have come because I fought with the others. It can last for one day to a week. I had to go to the toilet on the spot, in the drain in the room. The staff slaps and hit me often, already three times because I peed and got angry. Tell the government, I want to go home."

<sup>2. &</sup>quot;Mental Health Law and the UN Convention on the Rights of Persons with Disabilities," *International Journal of Law and Psychiatry*, May 2014

<sup>3. &</sup>quot;Living in chains: In Indonesia, mentally ill kept shackled in filthy cells," CNN, Kathy Quiano, http://www.cnn.com/2016/03/20/asia/indonesia-mental-health/index.html

<sup>4. &</sup>quot;Living in Hell: Abuses against People with Psychosocial Disabilities in Indonesia," Human Rights Watch, March 20, 2016









Confinement Cells





Individuals like Rafi, living with psychosocial disabilities, experience culturally embedded stigma and discrimination, as well as a variety of barriers in accessing their civil, economic, social, and cultural rights. These challenges are then magnified by the reality of poverty, hunger, lack of education, undertrained or non-existent mental health workers, cultural morays, spiritual beliefs, and conflict.

The new Mental Health Law called "Indonesia Free from Pasung, 2014" was created in an attempt to better promote mental health awareness and create more humane and effective patient treatment, mandating that every province must have at least one mental health hospital. Even with this mandate in place, however, there are only 48 mental health institutions and roughly 700-800 psychiatrists divided in various locations in Java and Jakarta. That translates to about one psychiatrist for every 350,000 people. More than half of the psychiatric hospitals are in four of the country's 34 provinces, while eight provinces have no psychiatric hospitals at all. According to the Human Rights Watch, the few facilities that do exist often continue the tradition of pasung, inflicting brutal and abusive treatment on those with psychosocial disabilities.

"They call my name, put medicine in my hand and ask me to drink it.... They don't allow me to refuse," said Wuri, a woman with a psychosocial disability living in a rehabilitation center. "They make me swallow the medicine and if I don't drink it, they put me in the isolation room." Human Rights Watch found that in four of the mental hospitals visited that patients were administered electroconvulsive therapy (ECT) without permission. In three of the hospitals, ECT was dispensed in its "unmodified" form. This means it was given without anesthesia, muscle relaxants, or oxygen. "Unmodified" form ECT decreases the physical safety of a patient but is common because of a scarcity of trained anesthesiologists to administer the pre-medication, lack of modern ECT machines, or because the modified treatment is simply unaffordable for patients.

Known as the daily "rubbing treatment." Haji Hamden chants as his assistant Abdul uses a hard implement to massage Sumbogo. Sumbago shouts his prayers throughout the proceedure. (right)



Ibu Maliah cooks lunch for the 280 men and women held at Galuh Rehabilitation Center in November 2012. She is assisted by former residents Siti, who had been living there for ten years, and Datir, a transgender man who had been at the shelter for thirteen years. Government assistance consisted of two months of food supplies. No one was turned away if they could not pay. (top right)

Meta was brought to Galuh suffering from mental issues complicated by drug use. For eight years she has lived without privacy in a large outdoor cage separated from the men by a wire wall. Sarja, one of the 40 member staff also lives at the shelter. (bottom left)

A woman lives shut in a room built behind her family home in Ponorogo, East Java. She is forced to eat, sleep, and defecate in this room. Other than one month spent at a hospital, she has been in pasung since 2003. (bottom right)







Rights of patients are minimal to none as family members or guardians are permitted to admit a child or an adult with a psychosocial disability to an institution without their agreement. None of those with psychosocial disabilities interviewed by Human Rights Watch who were living in institutions said that they were there voluntarily. In response to the lack of rights, Yeni Rosa's Damayanti's, of the Perhimpunan Jiwa Sehat Indonesian Mental Health Association (PJS) says, "The right to seek, choose, and receive care in Indonesia is left to the family. So, the patient has no right to Informed Consent in Indonesia. Even the Mental Health Act says that Informed Consent can be passed on by a psychiatrist from the patient to their family. Every time we visit an institution, we are always approached by the patients in the institution who plead with us to help them get out. Only people with mental illness are imprisoned without legal proceeds. People who are locked up in the institutions are no different from those locked up in prison, probably even worse. At least when you're imprisoned, there's a definite period of time. Maybe you will have a six month's sentence or two years. In the institution, you won't know how long you will stay."

Samsul Ma'arif family shelter in Brebes, Central Java, is one such place where patients are living like prisoners in traumatizing and discriminatory conditions, chained to platform beds that are collapsing inside of a shelter inundated by rats. Mustofa is the sole assistant at Syamsul Ma'arif family shelter. He gives the residents showers by pouring a bucket of water over their head. Akrom was a resident whose ankles and feet were swollen from being bound with chains, and he was suffering from profound malnutrition. After living here for one year and several months, in January, 2013, Akrom died. Mustofa clearly remembered the tragedy: "He did not die at his home. He was sick for a long time at the Shelter, and died in the same room after bath time." Kyai Syamsul, who runs the shelter, admits that he does not know how to help many of the men and women under his care. He is only able to use the method of treatment he learned from his father.

Haji Hamden, an Islamic faith healer, chants as his assistant Abdul slaps the leg of a shelter resident at a traditional healing center in Cianjur, West Java. Abdul uses a hard implement to massage patients, causing extensive bruising as part of the daily routine. (right)



Pondok Pesantren Bina Ahlaq is considered a boarding school and requires a tuition fee. It now houses about 200 students suffering mental distress. (above)







Mental health reform is complicated, and divided between the Ministry of Health overseeing mental hospitals and the Ministry of Social Affairs responsible for shelters for the mentally ill. According to Ministry of Health data, nearly 90 percent of those who may want to access mental health services cannot. There is a dearth of community-based mental health services, difficulty locating these services, and problematic access to medication. Even families with insurance can lack sufficient funding essential to medical and psychiatric services.

Besides logistical challenges, however, there is also widespread belief throughout Indonesia that mental illness stems from a lack of faith or sinful behavior. It may be caused by mystical spells cast by ill-wishers and ill doers, or by possession by evil spirits and the devil. For Indonesians, it is more acceptable and less financially burdensome to attribute confusing or abnormal behavior to spiritual weakness, spells, or possession. There is no stigma attached to being under a spell or possessed. As a result, shamans and traditional healers continue to remain the common choice for mental health care. Families typically first consult with these healers who rely a great deal on prayer or healing through spirits and magic. According to Dr. Pandu Setiawan, the former Director General of Mental Health under the Department of Health, "Even when mental health care is easily accessible, because of beliefs like these and the shame attached to the stigma surrounding mental illness, families commonly seek medical advice only as a last resort." Instead, they take their family members to traditional healing centers, where they are commonly subjected to crowded, poor conditions overseen by untrained staff, lacking medical treatment options, or psychiatric consultations. These facilities are often extensions of the healer's home. Sometimes they are designated as a "school" and the men and women held there as "students." Here, people may be forced to eat, urinate, and defecate where they are shackled.

Sofyan Hadi, Abdul Rahman, and Hero Caryoka admit a man brought in as a rescue. Galuh has been promised a pilot program that will fund professional mental health care assistance as well as training for staff. The goal for the program to begin in 2013 was not met. Galuh has been vilified in the international press. (left)





A man hugs the pillar at Galuh Rehabilitation Center. He has no access to sanitation facilities until the staff decides he will be cooperative. (top left)

At Pondok Kasih, a private Christian shelter licensed by the Ministry of Social Affairs, men and women are rescued from the street or brought by families. The faith-based treatment consists of song and sports, anointing with oils, and fasts, as well as "prayer and compassion." No fees are charged. Psychiatric consultations and medications are not offered. (bottom left)

An afternoon rainstorm pours through the leaking roof and onto Cakim. When the rain came a cooler breeze arrived. The flies were gone. (bottom right)





One such place called Yayasan Bina Lestari is funded in part by families of patients, as well as out of the pocket of the healer, Kyai Mundzir. It is a place with about 5 female and 15 male residents. Their method of therapy is that the patients must bathe every evening at midnight and then pray together. Kyai Mundzir leads that activity. He has two assistants. One of the assistants, Pak Ali, talks about the animosity felt between the patients and defends the shackling: "Sometime they fight each other, so they must be chained." He also says, "Sometimes the male patients fight each other, and harass female patients." The shelter has few rooms split between male and female patients. The rooms have no doors for privacy.

Another center, Pengobatan Alternatif Nurul Azha is a more traditional healing center, in Cianjur, West Java, where families pay for housing and the patient receives daily "rubbing treatment" provided by Haji Hamden, an Islamic faith healer. As part of the daily routine, Haji Hamden chants while his assistant slaps the legs of shelter residents, or uses a hard apparatus to massage patients, causing extensive bruising. Patients shout out prayers during the process. The decisive factor for a patient's discharge is based on a random belief. Haji says, "When the (body) heat becomes cold, they are ready to leave. When I take them outside to the market or to play football and the person feels cold, it means they are cured."

On March 21, 2016, Human Rights Watch released their report: Living in Hell, addressing the brutality of pasung. In attempts to create change, The Human Rights Watch called on the Indonesian government to:

- Amend the Mental Health Act and Rights of Persons with Disabilities Bill to ensure that they are in full compliance with the CRPD.
- Ensure rigorous monitoring and implement policies, including the ban on pasung, to prevent and redress abuses against persons with psychosocial disabilities.
- Train and sensitize government health workers, mental health professionals, and staff in institutions to the concerns and needs of persons with psychosocial disabilities, and create a confidential and effective complaint mechanism for individuals with psychosocial disabilities to report abuse.

- Progressively develop adequate and accessible voluntary communitybased mental health and support services.
- Work with international donors on programs and appropriate services, with donors providing technical assistance to such community-based services.

Dr. Pandu Setiawan, told Human Rights Watch: "The government needs to make mental health a priority because it's a human right."

Indonesia's Minister of Health, Nila Moeloek, committed to providing mental health medications in all 9,500 community health centers (puskesmas) across the country. "Achieving this could turn the tide against shackling," wrote Kriti Sharma, a Human Rights Watch Investigator. However, despite the subsequent international response to the 2016 HRW Report, actions by Indonesia's Ministry of Health and the persistent efforts of Indonesia's Mental Health professionals and activists, "little has changed," according to Andreas Harsono, Indonesia's researcher for Human Rights Watch (September 9, 2016). Most recently, "The Health Ministry has taken steps to train staff on mental health and is providing mental health medication in 2,000 puskesmas (community healthcare clinics). They hope to reach all 9,500 by 2019," says Kriti Sharma.





In 2016, the Indonesian government passed the Disability Act. One year later, Yeni Rosa's Damayanti's organization, Perhimpunan Jiwa Sehat-Indonesian Mental Health Association (PJS), became involved in the formation of a law that regulates shelters. "PJS has been advocating the Indonesian Disability Act for a while now. It was passed September last year by the House of Representatives. It is not perfect but it is a start. One of the mandates of this new law is to set up Government Regulations in guidance of the law. One of these protocols regulate social rehabilitation institutions (panti). This is a tremendous opportunity for us since PJS is involved as a drafting team for this regulation. If we do this correctly, we can create a strong legal base to stop all violence and degrading treatments in the pantis," says Yeni Rosa Damayanti. She also says, "If someone wants to build an institution, then there must be licensing and specific conditions for those licenses. At this time, nothing has been done by the Government."

The conditions are:

- the person who wants to build an institution must be a trained professional
- the patients who inhabit the institution must be willing to adhere to the service standards
  - PJS makes those standards of service

In an interview with Dr. Irmansyah, former Director of Mental Health at the Ministry of Health, now Chairman of a medical committee at Marzoeki Mahdi Hospital in Bogor, he says, in regards to improving the quality of care of the centers of healing or shelters, "In the PP (Peraturan Pemerintah or Government Regulations), care in psychosocial rehabilitation centers must be executed by professionals, or professionally based on the principles that are proven to be beneficial. By doing so, it will be necessary for institutions to provide services by trained professionals. This will indirectly ensure training is a requirement to fulfill the mandate from PP. The Government regulations will then require care in these psychosocial rehabilitation institutions to be carried out according to professional standards."

In Indonesia, the treatment of individuals with psychosocial disabilities needs to not only be addressed but completely revamped. In an effort to free those suffering from pasung, the Ministry of Health and the Ministry of Social Affairs have taken the initiative to create Standard Government Regulations (SPM), and Minimal Service Indicator (MSI). These indicators require varying regions in Indonesia to provide access to treatment for people with mental illness that are currently underserved. Some provinces in Indonesia do not have a single psychiatric hospital.

Even with government regulation in place, however, individuals released from pasung are often sent back. Government funding for programs is severely lacking. There is little infrastructure, and the implementation of regulations or programs to assist people after being released from pasung is uneven throughout the country. Individuals with psychosocial disabilities continue to receive improper treatment, be stigmatized, relapse, and live a cycle of incomprehensible abuse. Dr. Irmansyah says in a recent interview, "Adherence to treatment is indeed a major problem in the tackling of 'pasung' or mental disorder in general. An array of mental disorders including schizophrenia or bipolar are often suffered by those who are shackled, and they are chronic and recurring conditions. Obviously, adherence to taking the medication is absolutely necessary to prevent recurrence." He also says, "Failure to provide access to appropriate medication is often due to a limited availability of the drug in the area itself, or at the Community Health Center where the patient is located, or is due to the family themselves. There are no resources that could ensure patients continue to take their drugs." He adds, "Community psychiatric programs designed to prevent patients' relapse are not well implemented everywhere. Therefore, it is not surprising that many people with mental illness relapse. Eventually, their families return to their prior attitude that the care at psychiatric hospitals is a waste, and not effective. After that, the people are back in pasung."

Although the Indonesian government has set down regulations, there is a lack of governmental funding being directed into this area of concern. Training programs for doctors and nurses have been created but the government budget





is too scarce for these programs to be effective. Oftentimes health organizations don't supply enough medication. However, in an attempt to educate the public and create a deeper awareness devoted to mental health, there is an Autism Day, Suicide Awareness Day, and Bipolar Day. Systematic data collection on mentally ill people living with Post-Traumatic Stress Disorder due to pasung, or sub-par treatment in centers, is sorely absent.

According to mental healthcare experts, the making of a Mental Health Service System or Database of Mental Health Services in particular would not be easy. It would have to include data collected from psychiatric hospitals and government-run rehabilitation centers, plus information from traditional or faith-based healers, private unlicensed/ licensed rehabilitation centers, and boarding schools that admit mentally ill students. Even then, persons with psychosocial disabilities hidden in homes or living on the street would remain a challenge to find and include in the process of accurate data collection. According to Dr. Irmansyah, to construct a database would require "extra strength, extra thought, extra budget, and also a comprehensive collection process." Indonesia is a vast area with a spectrum of different health facilities, all with various capabilities. Health care workers have differing abilities and trainings. "In addition, informal healing or treatment information is not included in the health system. So, assembling all the various kinds of data together, undeniably, requires extra effort."

Yeni Rosa says, "The program that has been running is the "Free from Pasung" program. My main criticism of 'Free from Pasung' is that it addresses only the medical aspects. To end pasung, the approach must be comprehensive across all sectors. So in addition to the medical aspects, social and economic aspects should also be addressed.

As it stands, the 'Free from Pasung' program functions only to find people who are shackled and then brought to a mental hospital regardless if the situation at the mental hospital is adequate or not. Conditions at the mental hospital could be very poor. Shackling is moved from home to the mental hospital. In the mental hospital, they are forced to consume drugs without adequate consideration of whether there are resulting negative side effects. They are forced to drink it up. Finally, they return home with a prescribed bag of medication. Done. That clearly does not solve the problem."

With a severely broken mental healthcare infrastructure and a large vulnerable population, Indonesia struggles to eradicate pasung. Although there has been some progress, little has been sufficiently implemented. There is a need for more successful execution of established rules, regulations, public education, and mental health training within hospitals, all forms of shelters, and community centers. To end pasung, it is necessary for there to be ongoing collaborative work between policy makers, NGOs, human rights organizations, mental health organizations, local government, educators, and community outreach programs. There is a need for a more generous budget to be directed into the Indonesian mental health system, creating a more affordable and equitable mental health care system within communities, as well as providing a higher level of professionalism in protecting the human needs of patients. Deconstructing stigmatization and bias in the culture needs be more effectively addressed, as well as creating easier access to psychiatric facilities and medications. Most significantly, the basic human rights of individuals with psychosocial disorders need to be fiercely defended and honored, as these individuals deserve to live, like any other, with dignity and self-respect.





#### **Andrea Star Reese**

Andrea Star Reese is documentary photographer based in New York. Ms. Reese received The Lucie Award-Deeper Perspective Photographer of the Year in 2016, the 2014 David Pike Award for Excellence in Journalism Photography, Best Social Documentary from the 2009 New York Photo Festival, and was a finalist for the 2011 POYI, World Understanding Award. Other recognitions include: International Photography Award and a Julia Margaret Cameron Award, to mention a few. Most recently Reese contributed to Innovation & Equality, a photography series and exhibition by United Nations Development Programme 2017, and The First One Hundred Days, an International Center of Photography Museum window projection. Other exhibitions include: Visa Pour L'Image Perpignan, Musee de L'Elysee, and Angkor Photo Festival in 2013. Another project, titled, Urban Cave, a documentary on unsheltered men and women living underground in New York City was published in 2015 by FotoEvidence. She has been published around the world including credits to: CNN, Time, Huffington Post, The Guardian, BBC News Alerts, Al Jazeera, New York Times Lens Blog, and many others.

### Loretta Oleck

Loretta Oleck is a clinical social worker/psychotherapist and a poet/writer active in both mental health and human rights issues. For over two decades, she has worked in private practice treating individuals, couples, and families. Blending her interests, she worked on a Syrian Refugee Camp in Greece providing relief to traumatized children. She has authored six books in the field of mental health, as well as two poetry collections, Songs from the Black Hole and Persephone Dreaming of Cherries. She was a 2016 Pushcart Poetry Prize nominee. Her poetry has been published in The Stockholm Review of Literature, The Missing Slate, Obsidian Literature, Black Lawrence Press, So to Speak: Feminist Journal of Language and Art, Feminist Studies, Poetica Literary Magazine, WordRiot, Cultural Weekly, among numerous others. Her poetry was filmed for the Public Poetry Series, included in Best of 2013 Anthology (Storm Cycle), and performed at dozens of venues. She is a long time organizer of poetry readings throughout New York.

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