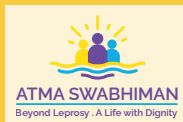


Stories that INSPIRE

Stories of hope, struggles & joy



An initiative of:





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Bringing Water to the Community

“I was punished many times during school days for being late, as I used to spend hours every morning fetching water. We had no drinking water or sanitation. It was very difficult to manage during the rainy season, it was also a pathetic situation for young girls and women to daily find a place to attend nature’s call..”

Goonj is a non-governmental organisation headquartered in New Delhi, India which undertakes disaster relief, humanitarian aid and community development in parts of 23 states across India.

In the 1960s people affected by leprosy started living together on government land close to Jharia Railway Station - the most convenient place for begging, seeking alms and for travel. In the late 1990s, the region was declared 'high-risk'. This was due to underground fires and land sinking as it is a coal mining area. This resulted in the closure of Jharia Station, leaving the community on its own. Gradually the location benefits along with water - stopped.

For more than twenty years, the women and children of the community had to fetch as much water as they could even though it was contaminated. The well is about 200 meters downhill - it is impossible for people with disabilities to fetch and so they depend on others to help - requesting, pleading. Sometimes in the dry summer months, it is impossible to find help. Purchasing water is beyond their capacity. The community did not even have a single toilet. One resident said:

In April 2021, Tarulshree joined Atma Swabhiman as a Hotline team member. While working in the team, she started to conduct community meetings in her colony to understand the problems. They decided to collect Rs. 20 per family on a weekly basis and to resolve the water and sanitation problem.

Her efforts were not limited to collecting funds. With the help of senior team members, Tarulshree got in touch with government officials, the water department and a member of the legislative assembly to lobby for the return of running water to her colony. The process was difficult. But somehow, with much effort, the government agreed.

People affected by leprosy were hired as labourers - giving them a source of income as well. Additionally, Goonj agreed to provide support for construction materials and dry rations for the community under their 'Dignity For Work' programme.

Finally, after four months of rigorous efforts people were able to restore the water in the colony.

It was a unique example of bringing together many stakeholders and effective utilization of resources with a sense of ownership and responsibility within the community.

Now there is relief for all the people of the colony as they have easy access to water!


I live in Ballugadda colony with my family. We are a colony filled with families who care for each other. My life has been tough. I have faced and continue to face, many struggles daily. Our financial situation is so bad, we don't always have food to eat. This is the situation of everyone in the colony, not just my family.

When Covid-19 hit and a lockdown was announced, no one could work anymore. For the first two months, our family had food, however, after that, my father fell critically ill. He began bleeding from his nose, ears and mouth. We were in a crisis. We didn't have money to take him to the hospital and his condition worsened. At that time of great stress, Atma Swabhiman provided us with some relief by giving us dry rations. Then, the other families of the colony pooled together some money so we could take my father to the hospital.

Every single contribution counted. With the help of my community, my father was taken to the hospital and given the care he needed.


I am very grateful to Goonj who provided us with food. From the lockdown, I learnt how dire our situation was. I also learnt the importance of family and helping those in need. Despite our situation, I now have hope for a brighter and better future.

Ragani, young adult from the Resident Ballagudda Colony



I have hope for a brighter future.





The troubles I have faced in my life

I was born in the 1980's and lost my parents when I was very young. At the age of nine, I began showing symptoms of leprosy. My brother's wife used to scold me until I broke into tears. They kicked me out of their house when I was twelve.

I somehow ended up in Kumardubi railway station where I saw people who were in the same condition as I was. A group of us made our way to BMP leprosy hospital and rehabilitation centre, Dhanbad, Jharkhand for our treatment. There, I was treated and cured but was left with permanent deformities. When I turned 15, the hospital staff got me married. Since then I have been living in Bankati leprosy colony, Jhariya, Dhanbad. I am blessed with three children, one boy and two girls.

The past 20 years have been a struggle for my family. I am not ashamed to say, my husband and I would go out begging to meet our daily needs. In February of 2020, my husband left the house to go begging as he usually does and never came back. As of today - March 1st 2021- there is no information on his whereabouts. I don't know if he's alive let alone safe. Soon after my husband went missing, the lockdown was announced. My children and I suffered greatly. There were many days we did not have food to eat. In December of 2020, my son went to Chennai to work as a labourer to support the family. More recently, I have been able to go back to begging to gain some more income for my family.

I have no regrets in my life. I am slowly overcoming the grief of losing my husband. I am grateful for my community that supports me. I only hope for a better future for my kids. A future filled with education and opportunities.

Sarothi Devi, Bankati leprosy colony


My name is Dhiraju Singh. I was eight when I was diagnosed with leprosy. My father took me to Nirmala Hospital, where I got treatment. Unfortunately, due to delayed treatment, I had already developed visible deformities in my hands and feet. My parents abandoned me in that hospital.

The director of the hospital admitted me to a boarding school. A combination of my deformities, devastation of losing my parents and demotivation, prevented me from completing my studies. Since then (1987), I started working in the rehabilitation training centre for my survival. Today, I am 42 years old living with my wife in the leprosy colony. She too is affected by leprosy. Together, we both work in the rehabilitation centre and earn about 1,500-2,000 rupees each depending on how much work we get. As we don't have any children, that small amount was enough for us to get by in life.


Other people in the colony would often resort to begging to meet their basic needs. My wife and I never resorted to begging as we tried to live our life with dignity. When Covid-19 lockdown happened, our source of income from the rehabilitation center stopped. We thought we would have to resort to begging to survive.

Here, Atma Swabhiman came to our aid. They gave us dry rations to help us survive. My wife and I decided to begin our own venture of selling vegetables in a small vegetable stall. Even for this, Atma Swabhiman gave us 5,000 rupees financial assistance to start our stall.

I can say now with pride we earn a profit of average 90 rupees per day with our vegetable stall and we are looking to expand it into a permanent structure.

A man with a beard and mustache, wearing a striped polo shirt, is sitting on the ground. He is looking down at a bowl of food in front of him. The background shows a brick wall and some sacks. The entire image has a blue tint.

Survival struggle with a hope of life with Dignity



The life I planned is disappearing before my eyes

I was born in an isolated leprosy colony called Nai Duniya Asha Vihar, located near a coal mining area in the outskirts of Dhanbad district of Jharkhand, India. Those of us living in leprosy colonies have completely different worlds from the rest of society. We have limited social interaction, fear of being ostracized because of where we live and limited opportunities in life.

As a child, I did not know why my parents were suffering or had any exposure to their lives. My grandparents raised me and my younger sister against all the odds. My father is an alcoholic and my mother left us when I was nine for reasons I still don't know about. Thankfully, I have always been good in my studies and received scholarships throughout my education. I am the only child who was selected for Navodya Vidalya from all the leprosy colonies - my first scholarship. During my school and college days, I always aspired to qualify for the Union Service Commission Exams (UPSC) and received moral support from my friends and teachers.

However, life has not been good. After graduating I returned to my colony only for the Covid-19 pandemic to hit. I struggled with poverty, sanitation, lack of environment to study and many such problems. My father is of no support and my younger sister is too young to help. I get some help from my grandparents, uncle and aunt but I cannot expect much from them because they have meagre resources. When I tried to find a job, I faced harassment, exploitation and vulgar comments from the people of my own society. The life I planned is disappearing before my eyes! I can't count the number of times I've tried.

All I want to do is find a job and get back on my feet!

Sujata

My name is Roopa Devi. I am 45 years old. I have been living in Ballugadda Leprosy Colony since 1987. I live with my husband, five daughters and three sons.

Our family survives on the little income earned by my husband from daily labour work and a more recently opened pork shop. The income is very low, only up to Rs. 100 to 150 per day. To shoulder the family responsibility, I also used to run a small tea stall in the colony, which shut down due to Covid-19. All the little savings we used to have exhausted to sustain the family during the difficult period of lockdown, including all shop raw material.

We had limited hopes to revive our petty business to what it once was due to lack of funds. The local money lenders charge up to 9% monthly interest, which is very difficult to repay while also facing exploitation and harassment. Then, in a colony meeting, I learnt about Atma Swabhiman's dry ration, medical aid and livelihood support programme. This was a great opportunity for me and I submitted my livelihood revival financial assistance request in the colony meeting, which got endorsed.

I received support of Rs. 5,000 from Atma Swabhiman to revive my tea stall and from the received funds I have bought utensils and material.

Today I serve snacks along with tea, which helps me to earn a little extra. I am happy to share that I earn approx 150 rupees per day from my tea stall. The earned income is a great support to sustain my family and a step towards a life with dignity!

A step towards a life of dignity

The children are our future

A group of children, mostly girls, are standing in a line outdoors. They are holding books or pamphlets. The background shows a simple structure, possibly a school or community center. The overall tone is blue.

People affected by leprosy living in Baniahir leprosy colony, Jharia, Dhanbad are largely dependent on rag collection and begging. The children also accompany parents in rag collection or are left unattended in the colony resulting in them being out of school and in trouble. Very few people are engaged in dignified work. The burden of this falls heavily on the women, children and elderly. After several efforts and community meetings, people have shown no interest in the development of their community. Finally, Atma Swabhiman took the initiative in involving the children of the community to lead the development programmes in the community.

In July of 2021, the Bal Panchayat was officially instated. Today the total number of members in the Bal Panchayat is 24 boys and 20 girls.

The children elected their own leaders:

- 1) Pankaj Mahto as President;
- 2) Sonu Rai as Secretary; and
- 3) Bhagirath Tanti as Vice President

For the celebration of Independence Day in August, the children came together and collected funds for the ceremony. They drew an Indian flag on the ground using natural materials for the colours. White colour using wheat flour; Green colour using green leaves; Red colour by crushing bricks. Together, the children came together and cleaned up the entire colony for the occasion.

Today the children are the gatekeepers and torchbearers of the colony. Each and every step they are taking towards unity, dignity and development of their own and the colony. We, Atma Swabhiman team members are also inspired by their efforts, unity and zeal to bring positive change.

Bal Panchayat

I am a 70 year old woman. I was born in Karmatand in Jamtara district, Jharkhand. I lived with my parents and three siblings. When I was three, my father passed away. My mother struggled greatly to raise me and my siblings. Because of our poverty, I was married off at the age of 11.

Soon after I got married, my illness took hold of me. My in-laws were disgusted by me. My husband abandoned me. Alone and helpless, I went to live with my grandmother. Because of my disease, I could go nowhere. I could not be allowed to be seen. My fingers and toes curled up. I began becoming weaker and more helpless. It was only once my entire body was affected by the disease that I learnt about the leprosy hospital and began getting treatment there. By then this disease had taken a formidable form in my body. I had big wounds on my leg. The doctor had to amputate some fingers, toes and one leg.

After getting discharged, I came to live in the leprosy colony. I re-married. I have 4 daughters who are all also married. My husband died and I live alone now. Through the Atma Swabhiman SHF project, I get medical assistance to tend to the wounds I still have on my legs. I am grateful for it.

Grateful for the medical assistance



Bhagi Devi



Rabi Bauri: A story of survival

I am 65 years old and have been living in the Baramasia Mersey Post colony, Dhanbad. My native place is Dokhra where I lived with my parents and six siblings. I used to go along with my father to take our cows and goats for grazing in the grazing field.


I was about 9 years old when I started showing symptoms. Nobody was aware of this disease in my family or the surrounding area and so I was left untreated. I lost my nerve sensation due to illness and my feet and fingers started getting blistered. I was not allowed to take a bath in a common pond so I started using field water for my bathing. Everyone stopped playing and talking to me which left me all alone. I was so depressed and cursing god for my situation.

Some people from The Damien Social Welfare Center (DSWC) came to my village for a medical camp. My parents took me there where we found out that I have got infected with leprosy. On seeing my condition the doctor suggested that I get myself admitted as soon as possible to the DSWC hospital located in Dhanbad. With a heavy heart, I left my family to get myself treated. There I saw many patients like me. It took me 4 years to complete the treatment.

After treatment, I came to this colony. We used to get free services for our ulcer care and monthly ration for every person/family. I got married to a leprosy-affected girl. We have two children. The DSWC supported our children for the education in their centre's school.

For years I have been living in the same colony. I worked as a daily wage labourer and my wife in a sewing centre. But everything changed during the pandemic as the government of India announced lockdown and everything just shut down. Like others, my family also got suffered during the covid pandemic. There was no bandages for ulcer care, no food because everything was closed and no money. The situation was so bad that I started begging in the temple with my wife so that we could buy some bandages & medicines.

The Atma Swabhiman team came to know about our situation and immediately extended a helping hand with dry rations and medical kits for wound care. We couldn't have managed our daily needs without them.



Pankaj Mahto on Bal Panchayat

I am Pankaj Mahto resident of Baniahir Leprosy Colony. I live with my parents. My father has a small godown which is our family's source of income. The Bal Panchayat was formed on 14th July 2021. We are a group of children between the ages of 6 and 18. Along with the President, Secretary and Treasure who were democratically elected within the members of the Panchayat, Tarulshree Bauri guides this Bal Panchayat on behalf of Atma Swabhiman. The main objective of Bal Panchayat is to help in the physical, mental and intellectual development of the children. The financial condition of the children in the colony is not good. Children are unable to pay school and tuition fees. For this reason, we study together in a group. The older children help the lower class children in their studies.

The Bal Panchayat has accomplished a lot. We have completed a cleaning drive of the community, an awareness campaign against the evils of alcohol and the respecting of fellow citizens, an independence day function with Tarulshree Bauri as chief guest and participation in many competitions of arts and sports.

Bal Panchayat participated vigorously in DFW (Dignity For Work) organized by Goonj Sanstha, Delhi. All the children and parents of this project of DFW cleaned the frozen drains and cleaned them very well. Participants received Goonj's DFW kit as a gift.

*President of the
Bal Panchayat speaks*

The community and the kitchen



The community kitchen was established on 14th August 2021 in Asha Vihar Kush Colony. Here, food is provided to the helpless and the disabled. For 10 rupees, a member of the community can eat to their stomach's full- a price unseen otherwise in this day and age. The kitchen was built mainly to feed people with leprosy who usually don't have the means to cook for themselves.

Daily worker Hari Parasad says:

"I am a daily laborer, with no certainty of when I will and will not get work. I used to go to a hotel for lunch, which was 30 rupees for a plate of food. For the past few days, I have been coming here to eat. The food is 10 rupees a plate and still very good."

Divyag Bhagi Devi a widow who is affected by leprosy says:

"I have 4 daughters who are married. I don't have a leg because of which I can't walk. For the past few years, I used to eat food in someone else's house. But now in the community kitchen, the women of the community kitchen bring me my food to the house and for only 10 rupees per plate. I get a lot. The food is good."

Ever since the establishment of Community Kitchen in collaboration with Goonj Sanstha, Atma Swabhimani and Sasakawa Health Foundation- Anjana ji along with two of her associates, Kamala Devi and Shankuntala Thakur, is successfully carrying forward this business. In the beginning, it fed around 40 people.

All the three women have decided that in future this kitchen will be taken to the district level, where 300 to 500 people will be fed daily. Currently, the community kitchen feeds food to 70 to 80 people at Rs 10 per plate every day.

A woman in a white sari is sitting on the floor in a kitchen, looking towards a silver teapot on a stove. The scene is lit with a warm, yellowish light, creating a somber and intimate atmosphere. The woman's hair is tied back, and she appears to be in a state of quiet reflection or distress.

Difficulties of circumstance

I was born in Gohali Saraikela, Raynagar. I lived with my parents, seven brothers and one sister. My mother died soon after my younger brother was born. My father was a farmer and the sole supporter of the family.

I did not know I had leprosy. It started as a wound on my leg. I attempted to get treatment for it but it was unsuccessful. When the villagers came to know about my disease, they stopped any contact with my family. I was not allowed to bathe or draw water at the pond. My father then heard of Dhanbad leprosy hospital. The disease manifested itself in ulcers so I got treated at the hospital. The ulcers were reduced but the discrimination from the people of the community did not. Because of the discrimination, my father brought me to live at the Jharia Kushth colony. In this community, I went to school, married my husband and had children. After my husband died, I have been living alone.

When the covid-19 pandemic hit, the lockdown caused me many problems. I live my life off of what I get through begging. During the lockdown, the situation was very bad. I had to tear up my old clothes and use them to dress my wounds. But then, Goonj and Atma Swabhiman provided me with medical kits for my needs. I thank them.

Mohkri Mahato

Educating the daughters

Sukra Bauri is 45 years old and came to live in the B.R.T.C. leprosy colony Dhanbad, Jharkhand with his parents. His parents were leprosy infected and kicked out of their village of Tetulmari, Jharkhand. They found themselves living in the Dhandabad station when two members of the Damien Welfare society found the family and brought them to the colony. His parents did not earn much and hence could not afford his education. Without much education, Sukra Bauri became a daily wage worker.

Sukra Bauri got married in 1999 and has two daughters. He is the only earner of the family and his wife Joshna is a housewife. Despite this, he spared no expense ensuring his children received the education he himself could not. With the covid-19 lockdown, his earning stopped and the family faced problems. The children could not continue their education and they found it difficult to put food on the table. There was a demand to pay school fees or have the children drop out of school. At this point, under the SHF programme, Atma Swabhiman provided the Bauri family with dry rations and 2000 rupees for the help of continuing the children's education.

Sukra Bauri

I am Anjana Mandal. I am 56 years old and live in Asha Vihar leprosy colony Jharia Dhanbad, Jharkhand. I have been living here since I got married in 1982. My parents were deformed due to leprosy. They lived without basic amenities and survived through begging and charity.

Today I work in our colony's community kitchen. My colleagues Sakuntla Thakur and Kamala Devi worked hard to establish this kitchen for our community. This is the first such community kitchen of this colony. After a lot of hard work, it was opened in August of 2021. The kitchen feeds 80-100 a day during afternoon hours.

However, we soon faced a big hurdle. The ladies working in the kitchen were beginning to get harassed and prevented from working properly. These people did not want the community kitchen to continue its operations without providing rent for the space we were using. After a community meeting, the verdict was officialised and we could no longer use that space to feed people.

My colleagues and I have found a new location to open the community kitchen and have reopened its doors. Despite the temporary shutdown and relocation, we still get 80-100 people coming to eat here every day. We are grateful for Atma Swabhimani's continued support despite our many problems and setbacks.

Forging through the odds

Anjana Mandal

The food stall

A woman wearing a patterned sari is sitting in a kitchen. She is looking towards the camera with a serious expression. The background shows various kitchen items like pots and a stove, all in a warm, yellowish light.

Mamata Devi is 38 years old and lives in Ballugadda Jharia, Dhanbad. She was born in Adra, West Bengal. She had 3 brothers and a sister. Her father was a daily worker and her mother was a housewife. Because their financial situation was not good, she did not go to school. She would stay at home and help her mother with housework. She had no exposure to leprosy or people with leprosy in her childhood.

When she grew up, she married Manoj Dom. He was a daily labourer who belonged to a leprosy colony. It was at this point that Mamata became exposed to the lives of people with leprosy. The colony accepted her with much love and kindness. She began to see the problems faced by the kind people of the colony and unlearned any bias she had against them.

Mamata and Manoj have 4 daughters and 1 son. Manoj is a daily worker who earned only 150 rupees a day. With the wish to educate her children and give them a better life, Mamata decided she wanted to contribute to the family's earnings by working. With her husband's help, she opened a fast food stall. The stall was a big success and her food sold out very fast.

In 2020, the lockdown shut down her food stall and all the earnings it gave her family. She used all her savings to feed the family as her husband could not find any other job. She needed help to support her family. At this stage, Atma Swabhiman stepped in to provide dry rations as a part of the SHF programme. Additionally, she was also given 5000 rupees to help restart her food stall. With this money, she has restarted the stall and been able to earn for her family again.

Mamata Devi

My name is Saligram Kumbhkar I am 65 years old. My father's name was Kandar and my mother's was Nukai. My father was a potter who made and sold utensils. My whole family depended only on my father's income. When I was a child, I always went out to help with my father's pottery work.

When I turned 25, a white spot appeared on my body and I didn't know what it was. I attempted to have it cured by homoeopathic medicine but it failed. My nerves began feeling irritated and my body became weak. At this point, my elder brother took me to Purulia hospital for treatment. I was already married by that time so my wife also became affected by leprosy. We both faced problems, pain and discrimination. The entire colony including my own family disowned us and we had to live on the streets for many years.

Eventually, we reached Bhowra Kusth colony where we lived for some years. From there, some kind people brought us to Kerkand kusth colony where we have been living since. When we came, there was not much in this colony but there has been a lot of development over the years and it is a good community. The people of this community helped build a hut for me and my wife when we first came here. This is our home.

When the covid-19 lockdown was announced, my condition was terrible. I had to go out begging to get money and food. I had no money to buy medicines or new dressings for my wounds. I began using old clothes to tie up my wounds and prevent them from getting infected. Atma Swabhiman and Goonj gave me great home during these desperate times by providing all of us with medical kits. They also sent a nurse to dress our wounds thrice a week. Because of their help, my wounds are now better and I feel some relief. I thank Atma Swabhiman and Goonj.



The colony is my home

I found community



I am 60 years old. My parents were farmers in my home town in Manbhum village in Purulia district. They died when I was really young. I don't even remember them anymore. My aunt and uncle took me in to raise me when my parents died but they didn't like me.


I was affected by leprosy when I was only 10 years old. My feet filled with wounds that would often bleed. None of the children played with me. No one came near me in fear of getting infected themselves. My uncle and aunt didn't care for me at all. I used to use leaves and old clothes to dress my wounds myself when they would bleed.

At 13 I had to work in farm fields to earn my own living. However, the wounds in my legs worsened to the point where I couldn't work anymore. I was soon kicked out of the colony. I then went to Loyiabad where I survived for many years by begging as I was unable to work in my condition.

I made my way to the Kerkand Kusth Colony. The people here did not live in amazing conditions but that was not what mattered to me. They were people like me who lived lives. They had huts, food, water and some electricity. They loved and cared for me. That was what mattered. Over time, the colony also developed more. We now have clean water and running electricity. So I've lived here ever since, begging to get by but a part of a community finally.

When the covid-19 lockdown was announced, my condition hit rock bottom. I could not beg. I had no money for food or medicines. The problems I faced during lockdown left me hungry at night and hopeless in my heart. But then, Goonj and Atma Swabhiman began giving out dry rations and medical kits. They even sent a nurse to dress our wounds. With this care from Goonj and Atma Swabhiman, my condition has improved greatly.

Budeshu Tuddu



In the Jharkhand district of Dhanbad, there is a small leprosy colony called Gandhi Kusth Colony. There are about 25-26 leprosy families here. Their livelihood depended on begging. Those who were young were daily labourers.

In 2020, when the lockdown was imposed they went through a lot of adverse situations. At that time some residents – Lalan Bauri, Raju Mahato, Balram Saw, Antu Rajwar and Santu Rajwar decided to start pig-farming. To start this business they approached Atma Swabhiman group for help and gave their petition as a result everyone was given Rs5000/- each. They started the business with the full support of all the members of the colony. Everyone contributes their leftover food for the pigs and supports the business. Everyone was happy and excited to grow the business.

Before, as daily labourers, the members of the colony would earn 150 rupees a day. Unfortunately, they would often not find work every day or consistently. Now, with this pig farm, they are earning 3,000 rupees per month.

Raju Mahato says:
“I am liking this pig-farming business. The leftover wastes of the houses are being used to feed the pigs. The profit margin is double. I wish a big pig farm would open in our colony and we would be known in society.”

Tasovar Ansari says:
“I am a member of this colony. I like this business of pig farming. All wastes are used to feed the pigs. And a good profit is earned through selling young pigs.”

Livelihood, a new life to change

A Value for Education



Khogan Karmakar was born in Pondava village, Jharkhand in 1973. His parents ran his household through begging. When he was five, he found out he was suffering from leprosy. Due to this, he was expelled from his village. He came to Gomo. Gomo's sister Marsheli supported him. He stayed there and completed his education till 8th standard. After his education, Marsheli got permission for him to stay in the leprosy colony at Dhanbad, Jharkhand.

In 2002, he got married. He had a daughter in 2004 and a son in 2008. He was a daily wage worker and his wife would go washing vessels in people's houses to earn money. Despite his deformities and their poverty, both of them valued giving their children a good education and sending their children to school.

With the covid-19 pandemic, they could no longer work and could no longer send their children to school. Through the SHF project, Atma Swabhimani provided their family with dry rations in addition to providing them 2,000 rupees for the education of his children. His daughter used that money to complete her 10th and is now in 11th. She wishes to fully complete her education. With that money, his son too could go back to school.

Khogan Karmakar

Sonia Bhuyan is a 35-year-old woman who currently resides in Bermasia Mercy Post. She was born at Dhansar, a coal field in Dhanbad. Sonia lived with her parents and seven siblings. Sonia's entire family used to go to pick coal and maintain their household expenses with whatever they got by selling it.

No one in her family knew about leprosy because of which, when she started getting white spots, they thought it was just some stain. As the spots worsened, her father would try to get her over the counter medicine to help cure it. This was unsuccessful and Sonia's illness worsened into physical deformities. At this point, she was not allowed to leave the house and was locked into her room in fear and disgust. For 5 years, she lived like a prisoner in her own house. Then, some people from DSWC came to her village to talk about leprosy. They were sent to her house. With her parents' permission, she was admitted to DSWC Hospital, Govindpur. This was the first time Sonia was around people who were like her. Her siblings never visited her in the hospital and she learnt that her parents died while she was getting treated. For better treatment, she was admitted to Barmasia Mercy Post Hospital. But here, the wound of her leg increased further, due to which one of her legs was amputated.

She then started working in the sewing centre of DSWC that was running in BRTC. She started with being paid 2,500 rupees per month but she quickly became an expert in sewing and with her skill, now earns triple that amount. While working there she married. They had a few years of happy marriage and had a kid together. However, after that, her husband turned to alcoholism and stopped working leaving Sonia as the sole earner of the family.

When the Covid-19 lockdown was announced, she lost her job. Sonia resorted to begging at the temple to earn some income and began using old clothes to bandage her wounds. Atma Swabhiman distributed dry rations, medicines and bandages in their community which helped her condition. They then urged her husband to go looking for work to help support the family. Sonia now takes care of the household while her husband goes to work. She feels hopeless as she wants to find work but their situation has improved from what it was before.

Stitching together a life

Sonia Bhuiyan

A photograph of a woman in a sari holding a baby, with another child standing next to her. The image is overlaid with a semi-transparent yellow box containing text.

My children have been saved from malnutrition

***Sundari shares that:
“Mr Rahul from Atma Swabhiman was there to arrange everything for my daughter medicines, fruits and also donated his blood to my daughter in case of emergency. Today my daughter is alive, all credit goes to team Atma Swabhiman as they helped me on time and took good care of my kids in my absence at home. I will try to take good care of my children and give them a good life.”***

Sundari Murmu is 38 years old single mother of four children. Her elder daughter Poornima is 15 years old, the younger daughter Rakhi is studying in 6th standard. Her sons are Gopi, 8 years old and Hobo, 4 years old. Rakhi is the only one of her kids who goes to school. Her first three children are from her first marriage to Karan Tuddu who had died of TB. her brother then arranged for her to marry her second husband who is the father of Hobo and also died recently.

Sundari Murmu's parents both had leprosy, both her husbands also suffered from leprosy. After the death of her second husband, she found it very difficult to feed her children. She is uneducated and does not know about malnutrition. Her eldest is used to eating soil and has stomach worms. Gopi has white spots all over his body and Hobo's stomach is swollen to look much bigger in proportion to his body. Sundari has asked everyone she knows for help and treatment for her children but all methods tried so far have failed.

It was July 2021, when Mr. Rahul and Madhusudan Tiwari from Atma Swabhiman went to Sundari's house for some work. They were shocked to see Poornima's condition and asked to get her admitted to the hospital immediately. Sundari shared her financial status with Team Atma Swabhiman, Mr. Rahul also contacted ChildLine for help but we did not get any response.

Poornima's condition was not good and she needed immediate medical attention so she was taken to the government hospital under emergency care and with the efforts of the team. After the check-up, the doctor suggested a few tests and started her treatment.

We thank the SHF Foundation and JAGO Foundation for guidance and support to our work in India. We are grateful to Mr Sasakawa for championing the inclusion of leprosy affected persons.

About Mr. Sasakawa

Yohei Sasakawa, born in Tokyo on January 8, 1939, is Chairman of The Nippon Foundation, a private, non-profit foundation established in 1962 for the purpose of carrying out philanthropic activities. He is the WHO Goodwill Ambassador for Leprosy Elimination.

Mr Sasakawa found that although leprosy was no longer a public health problem, there was still widespread stigma and discrimination against those affected by it. Since then he has strived to eradicate stigma and discrimination against leprosy in India. From his innumerable travels to leprosy colonies spread across India, he found that the fight against social stigma and discrimination would have to be led by leprosy-affected people. For this, he set up the National Forum of Leprosy Affected People (now renamed Association of Persons Affected by Leprosy).

How we started - The story of Atma Swabhiman

Sailendra was born in a leprosy colony and contracted it when he was 7. Fortunately, he was able to get multi-drug therapy (MDT) soon after diagnosis. He grew up watching his family and colony members suffer from the ills of leprosy and the society that casts them aside because of it. Once he completed his education and experienced some personal success, in 2004 he decided to give back to his community. It first started as a group of youth leaders comprising persons affected by leprosy. Together, they collected 1 rupee a day per family in all the leprosy colonies they knew and ended up raising 1,50,000 for the development of the colonies. This success is what motivated the entire community to come together and work for a better future.

Later, in 2009, the organization Atma Swabhiman (Self Dignity) was established for and by the persons affected by leprosy. His motto in life is to serve humanity by promoting a life of dignity and inclusion of leprosy-affected people in mainstream society.

Sailendra Prasad Shaw, Founder, Secretary, Atma Swabhiman

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***To make a contribution or support individual(s) from Leprosy affected Colonies, please get in touch :
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