



Birender Kisku, a 23-year old young adivasi (tribal), is from the village of Bijoypur village in Giridih district of Jharkhand, India. Bijoypur is about 10km from Bengabad, a semi-rural market place serving the villages around. Birender is the eldest in the family of six - his two brothers, sister and his parents. He lost his left arm at a young age.

Birender went to university but could not complete his BA - he was too weak to appear the final examination because of tuberculosis (TB). These days he goes to villages around Bijoypur explaining people how not to get TB and what to do if they have symptoms of TB.

Birender's parents wanted their son to have good education; they sent him to a school at Tilaya, about 15 km west from Bijoypur. The school was known for better education than the government school in the village itself.

But the following year, in 2003, Birender's grandfather became very ill. Birender's father spent all his money on treatment at a private clinic in Bengabad. The family could not afford Birender's school fees at Tilaya; he was shifted to a government school at Jhalakdiha where education was free. He lived nearby in Bichguda village with his uncle. Birender was in Class 2 at that time.

In 2006 when Birender was in Class 5, he had a serious injury while playing during lunch break at the school. He accidentally grabbed a live cable that was lying low by the playground and got electrocuted. His arm was badly burnt.

The local leader arranged Birender's treatment at a private hospital in Bengabad. His burn was very deep and serious - he was transferred to a speciality hospital at the state capital Ranchi. The skin and muscle tissue of his left arm were so badly burnt that the doctors at the hospital had no choice

but to amputate the arm. Birender lost his left arm at the age of eight.

Birender's wound needed regular dressings - the family had to stay in Ranchi for about three months. Staying in the city was not easy for a poor family from a remote village. On top of that, they had to buy costly antibiotics and dressing materials. Soon the family exhausted all the money they had in their possession. In the end, they decided to self-discharge their son from the hospital. Birender returned to Bijoypur. His wound finally healed after another two months.

How do poor families in adivasi communities afford medical treatments that require speciality interventions? First of all, such facilities do not exist nearby - facilities are in distant cities; also, people in marginalised communities cannot afford the bill of these super-speciality 'private' hospitals. Simply, medical interventions of special nature are not for the poor - this is the reality. The choice for these families, therefore, is to try what is available nearby, and affordable. Adivasi and other marginalised communities often opt for 'alternative' medicines in the form of traditional healers, herbal treatments



or sacrificing animals for bad spirits. Some try for proper medical treatments and raise money by selling their assets - jewellery, animals, trees, even lands they grow paddy. Even so, the money often falls short - therefore the treatment is discontinued or never tried at all. Deaths or severe disabilities are common occurrences in adivasi (indigenous) populated states like Jharkhand. Super-speciality treatment centres are privately run and in cities; and, the government's medical insurance schemes for the poor are more of political gimmicks. The reality is that patients in adivasi and other marginalised communities are yet to have access to simple treatable illnesses.

In Birender's case, his father Shivlal Kisku and his two brothers jointly raised money to cover Birender's treatment. They were a joint family at that time and it was perceived as a joint responsibility. Of the total Rs.45,000/-, the family could raise Rs.25,000/- and that too by working extra hours as manual labourers and by selling pigs and goats they had. For the rest Rs. 20,000/-, the family borrowed the amount from a moneylender - someone called 'Rupchandra Sahib' who lived in the nearby village of Mehabag. The interest was 5% per month, so Birender says! This was about 15 years ago. The interest has now doubled - 10% per month or 120% for one year. Shivlal and his two brothers together managed to repay the loan within one and a half year. That is not always the case for many families; some never come out of clutches of these private moneylenders.

Birender was lucky - he survived. He lost his left arm though. Birender has learnt to do things using one arm. Nowadays he rides a bike with a patient on the back of his bike to reach Ekta Niketan fifteen miles away.

After recovering from the operation (amputation of his arm), Birender joined school - this time another government school at Chitma. He was in Class 5. By 2014, he completed his matriculations and went to university.

For young tribal boys and girls, going to university is not common. Most look for work as labourers at a young age or get married. But Birender was keen for higher education - he continued his studies. Birender joined a BA course at a college in the Giridih town, the centre of the district. In 2017 he successfully completed the second year of the course and was in the final year. Unfortunately Birender could not appear the final examination because he developed tuberculosis. Birender returned to his village, Bijoypur.

He was very thin and weak because of the illness. His parents took Birender to a private doctor at Bengabad, like many other TB patients in the area do.

TB patients in marginalised communities in rural India often go to local private clinics than government run TB centres where treatment is free. Patients do not receive standard treatment at these private clinics - in no time they exhaust their money on various tests and injections. Patients discontinue treatment,

TB deteriorates, and some of them develop drug-resistant forms of TB - a common vicious cycle. Patients receiving treatment at Ekta Niketan, a community-based TB centre managed by a group of adivasi health workers, are mostly those who are victims of the cycle. [Please read 'Jhola Chhap and TB' at www.fourthworldaction.net.]

Birender met one such TB patient who was returning from Ekta Niketan with packs for medicines for TB. Learning about the TB centre, Birender decided to stop the private clinic - instead he came to Ekta Niketan for treatment.

In February this year (2019) Birender completed the full course of TB treatment and was cured. He started encouraging other suspected TB patients in his area to go to Ekta Niketan for treatment. Later Birender attended a training course at Ekta Niketan and has become a member of TB Action group - a group of ex-TB patients who regularly visit TB patients in nearby villages, and encourage suspected TB patients to go to nearest government TB centres or to Ekta Niketan for proper diagnosis and standard treatment.

Birender visits villages within 3 KM of Bijoypur. He explains villagers about TB and the importance of timely diagnosis and treatment; he sends suspected patients to Ekta Niketan. He even helps patients to reach the centre on the back of his by-cycle riding one hand.

Birender is an unemployed tribal youth from a poor family who has the real life experience of TB and the desire to stop the disease in his community. At Ekta Niketan, he discusses his work with Sunita. 'It is like a huge storm or a tide that does not spare anyone; TB not just kills a patient but destroys the whole family', he describes. He continues, 'making people



aware of the disease or timely treatment will not stop TB; we have to rise above poverty. Government schemes to uplift adivasi communities are not enough - we remain poor. And these days we have started losing our identity. In order to prevent the rising spread of TB in adivasi communities, we have to work with the younger generation to protect our culture and dignity'.

Birender is determined to fight against the spread of the disease.

[Written by Sunita Murmu in Hindi, one of the health workers at Ekta Niketan TB Centre]

To know more about Birender and Ekta Niketan, please write to ektaniketan@gmail.com.]