# Health issues of a branded community in an urban slum of Mumbai



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#### Introduction to NT-DNT communities

The 'De-notified Tribes' are those communities which were notified under the several versions of the Criminal Tribes Act (CTA) enforced during colonial rule in India between 1871 to 1947. Under this Act, the criminalization of communities engaged traditionally in hunting, fighting (as warriors serving the local rulers and chieftains), dispensing herbal medicines, fortune telling, taming of wild animals, singing, dancing and street performances was not limited to a particular region but covered the entire Indian territory. Post independence, the Indian Parliament repealed these acts, but despite this, the social stigma of criminality continues to follow them. The Act was based on a fallacious understanding of Indian society, particularly the caste system. T. V. Stephens, who was one among the influential members of the Law and Order Commission, equated the caste system with occupation and believed that most of the nomadic communities were criminals by birth; crime was their caste-based occupation as well as religion (1). These ideas were used to formulate the legislation under which certain communities were notified and termed criminal tribes.

Under this act, all members of the community were deemed to be criminals at birth and had to give attendance at the local police station on a given specific day and time, failing which severe punishment would await them. The free movement of these communities was restricted, and they had to take the permission of the local chieftain and the local police before leaving the place and settling in a specific area. If they failed to adhere to these restrictions, the penalties were severe. Apart from this, the local police had the authority to round up any member of the community on mere suspicion. Initially the *Hur* tribes from the Sindh province were notified under the Act; over time, other communities were included. In the year 1897, the Act was modified for the first time, whereby more stringent penalties were included. A compendium was prepared for the criminal tribes by the then Inspector General of Police of Bombay Presidency M. Kennedy (TAG Report, 2006).

After a severe criticism of the Act in India as well as overseas, the British enacted the Criminal Tribes Settlement Act in 1908, which ended up virtually imprisoning the criminal tribes in 'settlements' in the name of their rehabilitation. They had to live in a fenced area and had to take the permission of the guards to even answer nature's call during the night. The 1908 Act was modified in 1911, which

divided the legislation into four parts viz, notification, registration, restriction and settlement of criminal tribes. Major changes in the Act were brought in 1923-24. The changes were made to 'integrate the communities with the mainstream society' but the basic aim of the law was not altered. The act became a tool in the hands of the village officials to harass the community in legal way.

Major changes were brought in the CTA after 1937 when the Bombay Provincial Government appointed a committee under the chairmanship of K.M. Munshi to review the Act. The Munshi Committee recommended many changes and for the first time. Later in 1938, the Government of Bombay prepared a CTA Manual to clarify the rules and provisions under the CTA. After the formation of Provincial Governments, they repealed the CTA e.g. the Bombay Government repealed the Act in the year 1949 and the Madras Government in the year 1948. However, the CTA was replaced by the Habitual Offenders' Act, which was a back door entry of the earlier legislation, as it provided for establishment of settlements where habitual offenders could ne forcefully 'rehabilitated'. In the year 1952, the CTA was revoked throughout the country and all the notified communities under the CTA were declared as De-notified Tribes (TAG report 2006).

#### A brief introduction to the site of the study and the community

The site of the study is located along the Mankhurd-Ghatkopar Highway in the M-East Ward of Mumbai Municipal Corporation. Around 257 families of the NT-DNT community like *Masanjogis*, *Pardhis* and *Wadars* reside on encroached land i.e. private land since the last more than fifteen years. As this is private and encroached land, it is devoid of basic amenities and lacks essential services provided by the State to its citizens. Moreover their lack of official recognition and identity makes them voiceless to fight for their rights and basic entitlements. In this settlement, one finds communities that are totally secluded from the mainstream. All these are migrants from Maharashtra and borders areas of Maharashtra, Andhra Pradesh and Karnataka. They came to the city in search of livelihood and are mainly engaged in manual labour ranging from sewage work, cleaning of gutters to construction work. Entire families including women and children are involved in earning their daily bread, and their movement depends on availability of work at a particular site.

Often, if they get work in some other part of the city, they relocate to some site near their workplace and once the work opportunity gets over, they come back to their original settlement. There are no community institutions near this settlement. People have to walk nearly 3 km to reach the nearest

government health care facility, thus forcing them to go to private health care providers. A visit from the Auxillary Nurse and Midwife (ANM) or the Female Health Worker (HW) from the nearby Health Post is a distant dream. Even the Community Health Volunteer's visit is limited to the rare occasions. There are no community toilets, so open defectation is a common practice, and drinking and washing water has to be purchased from the neighboring slum. Alcohol consumption among the men and women is a common practice and domestic violence is accepted norms in the community.

#### Case studies on maternal health

#### Helplessness of being a woman

Eclampsia, 35<sup>th</sup> week gestation period; refused to go to higher facility; Age 17 years

A woman aged 45 – 50 years narrated the incident who had recently visited her relative's village on the Maharashtra-Karnataka border. She narrated the whole incident from scratch till the end.

The woman on the labor table was in some sort of pain. This could be made out only by the clinching of her fists or tightening facial muscles; there was not a slightest sound from her. Her poverty was evident from her clothing and by her tough mental conditioning which made it possible for her to bear the unbearable pain. It appeared as if the pain she is going through was nothing compared to the poverty or the sufferings she had undergone throughout her life.

The patient is lying on the labor table along with five other women, who were in the labor room. The labor table was devoid of any mattress; no linen, blanket or sheet to cover the women in pain. There were two nurses running around, writing something in a register and giving chits to the patients' relatives to get medicines from the pharmacy outside.

Unlike many other women, it had been a struggle and an achievement for this woman to keep her pregnancy till the thirty-fifth week and to reach the hospital. The woman had withstood her drunkard husband's beatings and minimum nutrition for herself and her unborn baby. The baby in the womb had also struggled to remain alive with the minimal nutrition. This was the day which was going to decide her fate and that of the baby, and the Darwin's 'survival of the fittest' theory as well.

The woman was suffering from eclampsia, a medical complication during pregnancy with seizures, high blood pressure and high protein in the urine.

As the hospital lacked the equipments and facilities to handle such cases, the woman was referred to higher facility in a nearby district which was 150 kilometers away from the hospital. The hospital was ready to provide ambulance for most of the distance free of cost and for the last 25 kilometers, the cost would have been minimal. It was for the woman to agree to the medical advice. But she refused to go

to referred higher facility.

The labor room nurse glared at the woman as if she was going to kill her if she refused to go; she wanted to free herself from this case – it would take her entire day and she would have to answer to her higher authorities in case anything unfortunate happened. She tried to convince the women in many ways; explained the complications of her condition and the consequences in case of lack of proper treatment, but in vain.

Now the question was - why was a woman suffering from eclampsia refusing to go to a higher facility. She found it futile to tell anyone present in the room her multiple problems - lack of money and parental support (she had lost them long back), her in-laws did not even care to visit the hospital, husband drunkard did not care for her, she felt alone and had come to the hospital along with a distant relative and her relative was not willing to accompany her to the referred facility.

At last the woman said, "Leave things to my fate. It doesn't matter if I am alive or dead. I am already dead to my in-laws and my husband. Let my baby die in my womb, rather than see this dreadful world. Let me stay back at the hospital rather going to a higher facility."

Karnataka has very good schemes for mothers as a demand generation strategy. For example, there is a maternal health care scheme called *Prasooti Araike* whereby Rs. 2000/- is given to the pregnant woman, one thousand during the first trimester and one more thousand post delivery, provided the delivery is done in a public institution, along with the *Janani Suraksha Yojana*. There is a free ambulance service to take patients within twenty five kilometres of the hospital and beyond that, at minimum cost to the patient to be taken to the referred hospital.

In above situation, who should be held be responsible?

#### Multi gravida with hemoglobin level 6gm/dl; post delivery complications; age 19 years

The woman in her twenties was lying on the floor with relatives surrounding her. The baby was one day old; there were no precaution taken to keep the outsiders away from the new born baby and the mother.

The mother belonged to the *Masanjogi* community, illiterate and married at the age of 14 years. This was her third child (a male); she had two female children from her earlier pregnancies. Her husband worked as daily wage labourer wherever he could find work. Her family was supportive to her. It may have been due to the sex of the baby that made them happy.

As her in-laws wanted a male child, she too wanted a male child to save herself from agony of their taunts. So at the risk of her life, as she had already borne two children within a span of three years and now her third child by the fourth year. Their socio-economic condition was poor and the consequences of these pregnancies had taken its toll on her health. But she was feeling relieved now; the consequences of not bearing a male child was worse than risking her life to bear a male child. There was pressure from all sides - society, family and friends to beget a male child. She expressed her feelings by saying that if this time it had not been a male child, her husband would have tried two or three more times for a male offspring, failing which, her life would take a different turn. As polygamy is practiced in their community, her in-laws would have taken the step of getting their son married again. Her status would have been reduced further if the second wife got them a male child in her first pregnancy.

The National Rural Health Mission (2005-12) emphasises women's autonomy in deciding their pregnancy and their health, but this does not seem to apply to this community. The missing link in this case is the Accredited Health Activist (ASHA) who works in the community. She has hardly any contact with the community which is fuelled by the hostile response of the community towards her. Due to the strong presence of patriarchal values leading to the male progeny syndrome, such cases are common in the *Masanjogi* community.

#### Gender, poverty and sufferings of a Masanjogi girl

A teenage girl was lying down in the shanty, three of her relatives sitting beside her. At the age of seventeen, she was trying to save her baby and become a proud mother. Her parents, in-laws and her husband were illiterate and the girl had gone to school till the third standard. They had got her married to one of her relatives, as is permissible and practiced in North Karnataka; neither the boy nor the girl was consulted. Soon after marriage, she was three months pregnant and referred to the general hospital, as she was found to be severely anemic (Hb level 5.5 gm/dl) and which would was life threatening for the mother and her baby.

The pregnancy could have been avoided through some counseling by the female health worker but was not been done. However, the parents took her to hospital as advised by the doctors. Her husband working was a daily wage labourer and could afford neither nutritious food not expenses on medicines.

Under the ICDS programme, every pregnant women should receive nutritional supplements from the *anganwadi* worker at the village level, but this girl did not receive any food supplement from the *anganwadi*. The State has launched and implemented many schemes for pregnant women in Karnataka, e.g. under the *Prasooti Araike* scheme, pregnant women receive one thousand rupees during first trimester of their pregnancy and another one thousand rupees post delivery along with the *Janani Suraksha Yojana* scheme. Apart from this, the health worker from the sub-centre is supposed to provide iron and folic acid tablets free of cost for registered pregnant women irrespective. Many a time, beneficiaries do not consume the medicines due to the associated gastritis and constipation that usually accompanies the consumption of these medicines. If there was someone to monitor this process, these incidents could be prevented.

#### Death of a woman with pregnancy complication, a case study through verbal autopsy

A woman aged 21 years from the *Masanjogi* community with three children and pregnant again with a fourth child in her last trimester, was suffering from abdominal pain since one week. She ignored the pain believing it to be a normal symptom during pregnancy. She had neither received ante-natal care (ANC) provided at public health facilities nor registered for ANC. Her last delivery was normal and conducted by the untrained birth attendant of the community at home. Hence, there was a similar expectation within the family for this pregnancy. Her husband, being a daily wage labourer, was facing difficulties in finding the work and had to support three children, his wife and dependent elderly parents back at native place. The family was illiterate and lacked awareness about free health care services provided to the mothers at public health facilities. For them, pregnancy was just part and parcel of life. As the husband said, "since generations, babies are delivered at home. No one in our home is born at a hospital. Nothing has happened to any one till date, and God willing, nothing will happen. If we have done any sin, God will punish me, or my wife or my unborn baby. There is no need to go to a hospital for delivery or pregnancy". As per the family, home delivery was the safest and common practice within the *Masanjogi* community.

Due to increased abdominal pain, she was taken to a private clinic in Shivaji Nagar. The doctor prescribed some medicines and advised them to take the patient to higher facility if the pain did not subside. Someone in the family said that during last child's delivery, her mother-in-law had taken a vow to appease God but it was not fulfilled; hence all the troubles in the family. If the vow was fulfilled, then the pain would subside and the delivery would be normal. So to fulfill the vow, the family went back to the native village, sacrificed an animal and performed some religious rituals before the village temple. Later, the delivery was performed at home by community's untrained birth attendant in the village. Post delivery, there was a complication leading to severe blood loss, as the birth attendant was unable to handle the case, and the mother was taken to a PHC. As the patient had arrived during the night and due to non-availability of equipments and infrastructure, she was referred to first referral unit. The first referral unit being in a Taluka place, she was taken to the nearest place. Due to the complication in the case, the FRU referred the case to a tertiary care hospital. On the way to the tertiary care hospital, the patient collapsed.

#### Early marriage and pregnancy related complication in the Masanjogi community

The family migrated to Mumbai fifteen years back from a village near the Maharashtra-Karnataka border. They are four brothers. One of the younger brothers is married (about four to five years back), and all of them stay together. The wife is approximately 17 years and is already a mother of two; a two-year old girl and a one-year old girl. She had one still birth from her first delivery. As per the mother (it is a dilemma whether to address her as a woman or a girl, so preferred to address her as a mother), she was married as soon she attained her puberty; she does not remember her age (she does not have a birth certificate). She is illiterate and contributes to household economy by doing menial jobs. She is happy with her married life, being a mother of two children.

In a year into her marriage, she became pregnant. Initially, she could not make out her pregnancy. Due to amenorrhea and frequent abdominal pain, she consulted a local doctor who confirmed her pregnancy. Everyone in the family was happy about the new arrival, but no one thought about the risks of early age pregnancy. The first trimester went without any problems but the problems stated in the second trimester. As the mother said, "everything was fine till the end of first trimester but during second trimester, I experienced severe pain in the abdomen. Despite the pain, they did not take me to a doctor; instead an elderly woman from the community gave me some medicine which relieved the pain." During the end of second trimester, she experienced severe pain in the abdomen. Again she received some medicine from the elderly woman, and the pain subsided gradually.

During second last month of her third trimester, she was taken to the PHC and referred to the First Referral Unit (FRU) due to an unbearable pain. At the FRU, an ultra sonography revealed intra uterine death of the baby. This came as a shock to the family. But the community believed that going to a doctor brought bad luck and made the baby die in the uterus. As per the traditional belief, going to a doctor during pregnancy is a bad omen which brings bad news to the family. The community believes that home delivery is safer compared to institutional delivery; the health personnel at the hospital do not provide good care to pregnant women because of their inability to pay money and their ragged appearance. As a family member said, "we usually don't go to government hospitals as the doctors and the staff screams at us and ill-treats us. Moreover, we prefer home deliveries as we have always had bad experiences in hospital - death of the mother or the baby, the baby becoming blind, physically disabled or mentally retarded."

#### The Curious case of a Pardhi pregnant woman

During enumeration of children in Jai Ambe Nagar, a *Pardhi* pregnant woman (with a one and a half year old and a three year old child tagging along with her) was giving her family details to us. Both spouses were illiterate; the husband worked as a daily wage labourer, and she too contributed to the family income by working. Currently, she was not working as she was in her third trimester. What came as a bit of surprise to us was that she was over forty five with seven living children, one still birth and not expecting the eighth child. Except her seventh child, all her deliveries had taken place at home with the help of an untrained attendant from the community. She had never ever received ante natal care from any public health facilities and none of her children had been immunised. According to her, all her children were healthy and therefore, there was no need of immunization. The seventh child was born in a hospital, but did not receive any immunization. The reason was simple - during her delivery, the hospital did not have the stock of vaccines, so they asked her to come back within two weeks. She never went to the facility, as she did not feel it was important.

"God gives us the children, no one should try to control the God's ways and has the right to do so. If you try to interfere with it, the family will have to face its consequences. If you get operated at a hospital for family planning, you might suffer from severe back pain, and sometimes there are examples of people dying after operation."

## Lack of accessibility of public health care facilities and consequent catastrophic health care expenditure

#### Facing indebtedness for not repaying a petty loan

Two families belonging to the *Masanjogi* community and hailing from the same village knew each other since decades. N lived with his aged parents in Mumbai. He had three elder brothers and three sisters who were married and staying at different places, busy with their own lives. His father worked whenever he could find some work; his mother stayed at home due to her age, and N worked as a daily wage labourer to support his parents.

T hailed from the same community; they were five brothers and two sisters, staying together with their parents in the same locality. All of them were engaged in some or the other and were comparatively in a better financial condition than the N's family. N had borrowed Rs. 50/- from one of the siblings of T. Three months had passed and N had not paid back the loan, despite repeated reminders from T. One evening, this led to a verbal fight between them; all of a sudden, T's brothers started beating N and in a fit of rage, one of them stabbed N with knife umpteen times till he collapsed. No one from the community came to help N. Later, a community leader intervened and disbursed the crowd. Since N was bleeding profusely, he was taken to the nearest private hospital but denied admission. This experience was repeated with similar results in three-four private hospitals; finally, N was taken to the nearest municipal hospital. Even here, he was denied admission and had to be taken to a tertiary care hospital. As there was good amount of blood loss and a deep wound, a surgery was suggested but the resident doctor was not willing to call the specialist.

After pleading umpteen times, the resident doctor did not budge. The community leader suggested that the family offers some 'good will' money to the surgeon. Soon after the family offered the 'good will' money, a surgeon/specialist arrived on the scene and performed the surgery. The family paid twenty two thousand to the surgeon/specialist for the procedure.

Post surgery, many other procedures had to be performed by the specialist and the family paid almost another fifteen thousand to the specialist; the injury was supposedly so deep that it was almost touching the kidney. The procedure was complicated and hence they had to pay the money if they wanted to save their son. The family could not understand the procedures explained by the doctors and they had to

accept whatever was told to them. After a month-long stay in the hospital, N was discharged. Since it was a medico-legal case, the police had to be bribed to file the First Investigation Report and to complete all other formalities. By the time N was discharged, the family had spent a total of forty five thousand on his treatment (including expenses like medicines, food, bed charges etc.).

The family was hesitant to complain regarding the bribe (as per the family, it was 'good will' money) paid to the doctors. As the head of the family said, "doctor is like God; does anyone complain about the bad doings of God? We won't complain about him as he has saved our son's life. The amount is negligible compared to his service."

#### Paying a heavy cost for not treating Malaria on time

A young boy aged around 18 years and working as construction labour was suffering from intermittent fever for the last one week. He took treatment for his fever from a nearby private clinic, but the fever did not subside. He visited another private clinic with no result, and the intensity of fever grew in the coming days. In this process, he wasted almost two weeks in getting treatments from various clinics resulting in an expenditure approximately Rs.1500/-. He had to finally be admitted to a private hospital and was kept in the Intensive Care Unit (ICU), as he had symptoms like shortness of breath, high fever and extreme weakness. Neither the patient nor his family members were consulted before admitting the patient to the ICU; they were not even explained the need for ICU admission. They were told to deposit Rs.10000/- as a deposit and their signature was taken in a form. Almost Rs. 4000/- was spent on various laboratory tests which revealed very low platelet count and decreased hemoglobin level, which is common in Malaria.

The tests revealed that it was a complicated malaria case; the patient was suffering from Plasmodium Vivax and Plasmodium Falciparum. He was kept in the ICU for four days and two days in general ward and was charged Rs. 22000/-, which the family had to pay by taking a loan from a money lender. The discharge was against the advice - this means that the hospital was not willing to discharge the patient but the family members forcibly got him discharged. The family lost their daily wage earnings; everyone was scared and out of fear, every member of the family remained present at the hospital for the entire period of stay of the patient in the hospital. The loss of income of the family and the loan taken from the money lender will push them further into the vicious cycle of poverty.

Malaria can be treated at minimum of cost if treated on time by private medical practitioners. The same treatment is available free of charge at the urban health post. But the patient did not opt to utilize the health care services from the public health facility due to their previous bad experience at the facility. The distance of the facility from the locality is almost 3 km, and therefore, acts as a barrier to access the facility. The timings of the facility (from morning to afternoon) are not convenient for people from the communities as most go to work in the morning and come back in the evening. They therefore prefer the evening hours and hence end up going to private medical practitioners despite the unaffordable fees they may charge. Moreover, the visits of auxiliary nurse and midwife, the male health worker and the community health volunteer to the area are few and far between, leading to lack of awareness about such diseases and services available at the facilities.

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