

Challenging Positions in Disability Research

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Baba Amte's Anandwan Leprosy Project shows world making
potential

Once in a while you will stumble upon the truth
but most of us manage to pick ourselves up and hurry along
as if nothing had happened – Winston Churchill

Aim: Lepers want parity not charity

Do not mourn for what you have lost
And do not insult what you still have
Make the best and most of it – Baba Amte

Method: Working with and listening to narratives during four long
stays

Memory is like a bud,
Its petals are tightly curled;
Open one, and the others loosen slowly.
One detail leads to another, until you get completely lost
Each memory clamours for inclusion

Findings: Muslim, Christian, Hindu leprosy affected come together
to draw a new road map for themselves in the Indian village of
Anandwan.

Sheikh Karim Mohammed and Salima Bi
Govindrao Fulzile and Bhagirathi Fulzile
Mahadev Kond and Leela

Life has taught us that love does not consist in gazing at each other
But in looking together in the same direction

I sought my soul, my soul I could not see
I sought my god, my God eluded me
I sought my brother, I found all three – Baba Amte

This paper is a study based on interviews with three leprosy affected couples who decided to come together and start their own little families within the large family of leprosy combatants in Anandwan. In these three studies I am looking at the life stories of the couples before and after their marriages. Their relationships with their kith and kin, responses of society towards them, the inner call to give expression to their instinct of love and care, and the efforts they put in to stand on their own feet and support one another emotionally, provide for their daily material needs, make savings for their old age and put aside that what is seen as surplus, for the betterment of their larger community of fellow differently-abled citizens in Anandwan. Not so long ago all three couples celebrated their silver wedding anniversaries with great joy and thanksgiving to nature and the Giver of life.

India is a multicultural and multi-religious society and home to people of every major religion in the sub-continent. For the present study I have taken three families: a muslim couple, a hindu couple and a christian couple who despite their past personal backgrounds, ethnicities and histories are forging fresh identities and building a new future for themselves in Anandwan.

Those hailing from our traditional Indian muslim background form a minute but a very visible and a dynamic group in Anandwan. In all

they are twenty men, eleven women and a few children. I met this beautiful person named Salima. She and her husband are both cured from leprosy. To close friends Mr. Sheikh Karim Mohammed has this to say, "I kept meeting her here and there..... We often met each other. Sometimes she would ask me for a few coins. She was often short of it. She wanted to buy lipstick, powder and face cream from the shop. Poor little girl, she was alone, her family never came to see her. I knew she would never be able to go anywhere so... I married her". He has a hearty laugh, shakes his head as though bemused, at how he came to find a life partner at "Anandwan" or in English "Jungle of Joy". The late Baba Amte used to say with delight, "these youngsters want to beautify themselveskids without fingers and noses and toes....that is my greatest joy".

The couple has been living at Sukh Sadan or the Abode of Bliss, a village commune within Anandwan that has around hundred households. They live in independent cottages with small gardens for fruit, vegetable and flowers around their dwellings. These are their kitchen gardens. For their immediate kitchen needs they pluck vegetables and fruits from such gardens. For beautifying their hair and homes and also for liturgical purposes the home grown flowers come handy. As a rule they prefer eating at the community kitchen, sometimes cooking extra delicacies in their own homes.

Like many others who entered wedlock in that era, Karim and Salima do not have their own children. Not having children used to be a precondition for the marriage of leprosy affected couples in the early years, as potential for infection with prolonged exposure was thought to be real and great. In those bygone decades medicines and state-of-the-art facilities to combat leprosy were still in their infant stages. Today Sheikh Karim Mohammed and Salima work in garden nurseries, caring for seedlings. In the same block at Sukh Sadan, there are three other families living in the adjoining units. There are always people to smile at and exchange greetings with during the work breaks and at the early hours and at sun set.

Sheikh Karim Mohammed is sixty-five years old. He says he had to combat leprosy from the time he was thirteen. During his first three years as leprosy patient he lived in his ancestral village near Yavatmal, some 150 kilometres away from Anandwan. When it came to light that Karim was suffering from leprosy, there arose problems in connection with the marriage of his niece. Remembers Karim, "neighbours used to say, the bride's uncle has leprosy. They prepared a hut for me outside the house, I lived for three years in that hut, food was given to me and I would consume it in haste. They brought the food to me when no one was in sight". At the age of 16 Karim lost his father and so the teen aged boy left for Anandwan. An elderly cotton merchant of the village seeing Karim's

plight advised him to give up that sort of secluded existence and go over to Anandwan. "I was told to take a bucket, one plate, a glass, two trousers and two shirts", says Karim. "On arrival in Anandwan I cried a lot but Baba Amte assured me that I would be alright. When at home, I used to pass away my time sleeping, day dreaming for the whole day, month and even more".

At the Anandwan workshop Karim was sent to learn spinning. There he began to make thread that fetched him some money. The Spinning Wheel used to be a major weapon in the armoury of Mahatma Gandhi. Generations of Gandhi followers have used the Spinning Wheel spirituality and kept themselves busy, constructive and productive at most times. During protests, fasts and life in prison, the spinning wheel used to be a constant companion to Mahatma Gandhi and his followers in their struggle for ethical demands, human rights and dignity in living. The thread they spun provided them with cloth, cash for their needs and immense joy in their exercise of remaining self-employed and independent. The exercise of spinning is conducive to meditation and concentration. Spinning is still carried out on daily basis in many Gandhian Ashrams or Homes for indigenous spirituality.

On account of leprosy, Karim's foot had to be cut off. Over the years he has worked at the Anandwan handloom, power loom and

at the tin can workshop. He has also worked as office attendant to Dr. Vikas Amte, the eldest son of Baba Amte who joined Anandwan after completing his studies in Medicine from neighbouring Nagpur University Medical College in the mid 1970s. Planting trees and looking after rose garden is something that keeps Karim busy, creative and content. On daily basis 15-20 people work with him in the sprawling rose gardens at Anandwan. He came as illiterate but through sheer motivation, interest and dedication, he made efforts to read and write during his free time. "Earlier people refused to come near me. Now people come to take flowers and rose saplings that I prepare through out the year. So too people are not afraid to take fruits and vegetables from my hands and eat these right before my eyes", Karim says with tears of joy as Salima offers me a cup of tea she has been busy preparing while the two of us chat.

Leprosy has taken away all of Karim's fingers but he still grows lovely roses. His wife Salima came to Anandwan in 1962. Her father had passed away when she was just an eight year old girl. Her father too suffered from leprosy. Salima came from a family of 10 children, seven brothers and three sisters. She hailed from the southern Indian city of Hyderabad but has lost contact with all her relations. Husband Karim loves her and the entire Anandwan knows her as Mrs. Salima Karim. She and her husband live in dignity and solidarity with the rest of the Anandwan life-world.

Our second couple are Govindrao Fulziley and Bhagirathi.

Govindrao came as a young leprosy affected orphan to Anandwan. He was just 7. He had four brothers and a sister but none of them had leprosy. The disease deprived him of the affection of his parents and the love and friendship of his siblings. "Baba Amte gave me my first short pants", says Govindrao with a hearty laugh. Baba Amte advised me to do my schooling in the Anandwan primary school". Though short in stature, over the years Govindrao has grown into a reliable pillar of strength at Anandwan. He has tried his hands at different works and possesses a sound knowledge of history and development of Anandwan. From being a worker in the construction sector, he has gone into agricultural fields, looked after chickens and ducks and supervised the beautification of the sprawling campus. The local village administration or Panchayat rule had Govindrao as one of its Board member and the inspirational leader made significant contribution during his tenure in the office.

In 1975 Govindrao married Bhagirathibai. She arrived in Anandwan because her first husband sent her away within a year of marriage because she was diagnosed as being affected by leprosy. Bhagirathi was then just around sixteen years of age, a newly married young teenager. Says Bhagirathi "it was an experience of total misery. I did not know what to do with my life. I came to Anandwan for cure and found the place and people very supportive.

I stopped thinking of going back". Govindrao and Bhagirathi fell in love and after a four year period of romance and marriage preparation, requested Baba to approve their marriage plans. The couple were united in a mass marriage celebration with 15 other cured leprosy couples, all from Anandwan. Such group or mass marriages are organized now and then to cut down on expenditure and to reduce the number of work hours that would be lost if they go in for individual marriage celebration for each couple. The entire Anandwan community running into a few thousands come to bless the couples and to partake in the feast that follows. Music, fireworks and special food mark such Rites de passage. Guests, well wishers and admirers fill the spacious Chief Minister's Hall which is especially erected to hold such massive local events of wellness and community making.

Since the Fulzileys were both leprosy patients they had to undergo sterilization. Hence the desire to have their own children could not be fully met. But that did not deter the couple from giving expression to the tender feelings of their hearts and life promoting initiatives. The Fulzileys have adopted a nephew by name Yuvraj, the son of Bhagirathi's elder brother. The boy was brought to Anandwan soon after Govindrao and Bhaagirathi were married. He did his schooling at the Anandwan Primary School, took lessons in vehicle repair and learnt driving. For a long time he worked as one

of the bus drivers in Anandwan. Later he got himself employed as driver in a small company in Warora, a few kilometres away from Anandwan. In February 2008 Yuvraj married Anita, an orphan girl from the neighbouring village. Some time back the young couple were blessed with a baby boy whom they named Sail. Grand Pa Govindrao and Grand Ma Bhagirathi are excited with the new arrival.

Govindrao tells me he loves and relishes the daily fresh food cooked by his wife Bhagirathi. Earlier he says, "I lived in the bachelors quarters where the young men cooked their own special dishes on holidays. On work days we used to go to the community kitchen and eat there sitting among big crowds. Gradually as we began to find partners, we dispersed and formed our own two member teams". Occasionally the former colleagues and room mates come together and have celebrations where besides other things they recollect and recall their experiences of the bygone times. These are special days that take them back to their common background rooted in their leprosy, stigmatization, marginalization, ostracism and neglect, a sort of new ethnicity if one may prefer to call it. In such gatherings and get-togethers, there is a special sense of camaraderie and bonding among the participants. A feeling of "effervescence" overtakes them, something in the line of a process as described by Emile Durkheim. Reviving and further generating

bonds of brotherhood and love for one another, they empower themselves with feelings of solidarity, courage and strength. The whole process generates ingredients that appear to contain traces of therapeutic value, promoting emotional well being and renewal of links so vital for community making.

Now we come to our third couple and we have Mahadev Sadhu Kond aged 65 and he hails from the State of Madhya Pradesh in Central India. He has been living for the last 40 years at Anandwan. He spent a long time working as driver and drove Baba Amte all over India, participating in his projects and struggles for the emancipation and empowerment of the downtrodden, marginalised, aboriginals and the displaced. Mahadev has participated in those series of movements of resistance in areas facing natural and man made disasters. Master mechanic Mahadev is also referred to as Motu Meestri or the "corpulent master " on account of his short stocky figure. He is an incredible source of first hand information about an important phase of Anandwan's social involvements beyond the borders and frontiers of leprosy and physical disability. When not on duty as driver across the country, he is based at the Anandwan Workshop assisting in the training of aspiring young future drivers and motor mechanics who see their vocation and mission as borderless and mobile citizens of Anandwan.

Mahadev comes from a family that has experienced leprosy as a common drawback in their lives. His parents, older brother and a younger sister were all leprosy combatants. When at home young Mahadev used to take treatment at the Protestant Mission Hospital in Baitalpur town and during that lengthy period was involved in a number of bread-earning activities. This was a phase that lasted almost 10 years. In 1964 he visited Anandwan and quickly decided to settle there hoping for a quick cure. But the stay lasted only 4 months. The visit and experience did him little good then. He was not impressed with the way things were done at Anandwan. He only saw fellow and often illiterate leprosy combatants doing all medical work such as diagnosis, cleaning and dressing of wounds, giving injections, making beds, cooking, serving, cleaning and even singing hymns and putting up dramas in the evenings. In those days Amte's Anandwan could not afford trained doctors and nurses like at the Christian Mission Hospital in Baitalpur town. Indian doctors and their families were mortally scared of the deadly disease and the weight of the stigma that went with those affected by leprosy. The assuring presence of medical doctors and the soft touch of qualified nurses which Mahadev saw and felt at Baitalpur was totally absent at Anandwan. Having experienced hopelessness, he went back to Baitalpur and spent there a decade fending for himself doing odd jobs to make ends meet. Ten years later in 1975, as a more mature young man, Mahadev once again returned

to Anandwan. Though not free from leprosy but just like all others before him, Mahadev's life and talents were highly valued by Baba Amte and his leprosy combating lieutenants. He was straight away posted at the Motor Workshop where through perseverance, good nature and hard work he has been able to carve out a special identity for himself.

Twenty five years ago Mahadev married Leela and has a 20 year old daughter who has completed her higher studies at the Anandwan College of Arts. The youngster is employed at the Greeting Card section run by Anandwan's Sandhi Niketan or House of Opportunities. This is how Mahadev was able to get a wife of his choice. His would-be-mother-in-law was undergoing treatment for leprosy at the Anandwan hospital. Like many of her colleagues she too had been driven away from home by her husband and in-laws. Daughter Leela and her other siblings used to visit their leprosy combating mom. It was during one of those visits that Mahadev happened to see Leela and he liked her good nature and polite behaviour. Thereafter every visit gave them more opportunities to see one another and that is how a lovely relationship developed between the two. There were some major differences though which they had to overcome. Mahadev was double of Leela's age and also an ex-leprosy combatant. Young Leela had never been affected by leprosy. Only her mother was a leprosy combatant. But as was in

the beginning, is now and in future still may be, children and relations of leprosy affected persons do carry stigma with them that hampers and limits their choices in terms of studies, employment, marriage and socio-economic opportunities.

Despite all objections Mahadev and Leela were married and Janaki was the fruit of their love, the first girl child born in Anandwan to a former leprosy combatant. Looking back Mahadev says, "my both parents were leprosy affected and lived and worked in the Missionary Hospital in Baitalpur. As young leprosy affected persons they fell in love. The missionary hospital in those days discouraged falling in love and the youngsters were released from treatment and expelled from the hospital. But their love was strong". The couple got married and Mahadev was the first fruit of their love. Mahadev says, "the earlier husband of my mother had deserted her when she contracted leprosy. I was born of parents who were both leprosy combatants. My parents became beggars on account of leprosy. No one gave them work. I could not go to school. So I went begging from place to place. Where I imagined I could get something, I went". His 80 year old parents passed away prior to his coming to Anandwan.

From the time daughter Janaki was born, Mahadev and wife Leela have been preparing and having food cooked in their own house,

before that they collected their daily food from the community kitchen. Mahadev recalls, "prior to my entry into Anandwan I worked lifting and carrying luggage, suitcases and parcels on my head from place to place. I sold toys, sweets and nuts in the trains and bus stations. Helped out in roadside film shows as operator, dug wells, washed plates whilst parents begged. The money I would earn, I would happily pass it on to my parents. I would gather broken rice from the neighbouring rice mills. In a week, I could collect 3 to 4 kilos of such discarded rice. I became a helper at a cycle repair store and then a helper at a motor mechanic outlet. When it was discovered that I was suffering from leprosy I was instantly sent away from the workshop. From the side of my father I knew no relations". At his village Baitalpur, the local church was one place he could frequent without being chased. Going to other public spaces was forbidden on account of leprosy and the stigma. "With my bruised heart and broken body I roamed the streets and forests in search of free space. I found the massive gates of Anandwan thrown wide open to me. I decided to stay and I am happy. Praise the Lord" – concludes Mahadev.

"The health of a society is measured by the condition of its lost, its last, its least", was often said by Baba Amte as did Mahatma Gandhi before him. Baba Amte refused to settle for a mere provision of a safe roof for the leprosy affected sisters and brothers. For the proud

Amte, what mattered more was the restoration of their self-respect and confidence. The key to Amte's work is his awareness that mere charity does not help. It only cripples the already afflicted. Leprosy is a disease that frightens death too. Elsewhere out of fear, the bodies of those who died were left to rot. But at Anandwan the dead are given a solemn, respectful and often a tearful burial in a well looked after graveyard. Each grave out there is provided with a flower bearing tree and flowers descend on the grave for a good part of the year. Many having no one in life plant trees in the graveyard trusting nature to shower flowers on their graves year after year !

At Anandwan, the principle that governs rehabilitation of the differently-abled is simple: sense of dignity through self reliance. If a person comes in to Anandwan with no eyes, then they examine the hands. If they too are gone they see if the legs are useful. Thus instead of agonising over the losses of the past, the effort is to retrieve what would otherwise be lost. The dignified citizens do not get their food as charity. They grow it. They are proud members of a large productive family. Anandwan's vision is much larger than the work relating to eradication and elimination of leprosy and the rehabilitation of those cured. It encompasses the view that work proclaims a person's religion, that human beings need to have more faith in fellow humans than in any other thing, and that society

needs to correct the deliberate distortions within it. Agency, community making and vision reshaping are dynamic and ongoing processes set in motion by our differently-abled citizens at Anandwan or the Jungle of Joy. Having had the privilege to live with them for long I must say I fail to notice their disabilities. What I see are only their multiple abilities and the rich ethical inspiration and material legacies they leave behind, as they march ahead defining and redefining their own lives and laying down fresh strategies.