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Engendering Change: Overcoming Difference and Disability

A profile of Nafisa Barot

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Nafisa smiles broadly, gets on to the sofa, puts her two crutches to one side, and says, “Let’s start this conversation!” This is how I’ve known Nafisa Barot for more than twenty years, as a friend, as the director of the Gujarat-based NGO, Utthan, a champion of women’s rights to water, and a global voice on gender justice and sustainable development. She passionately pushes aside all sorts of adversity, from being a Muslim facing social discrimination in Gujarat to a multitude of health challenges including being declared a paraplegic and fighting breast cancer, to persevere day after day on the issues she holds dear to her heart. For the countless times that I have travelled with Nafisa to the field, her crutches and her wheelchair carefully packed away, I have watched her being lifted by her team and carried for meetings in remote hamlets, and seen her enjoy the singing of her life partner and renowned theatre personality, Rajoo Barot. Humbled by her conviction and her courage, this is her story.....

Early years

Born in 1952 to a lower middle class Bohri Muslim family, in the small town of Mahu in Madhya Pradesh, Central India, Nafisa was a middle child, sandwiched between two brothers. As her father was a government-appointed radio engineer, she grew up in small towns across Gujarat, accompanying him to villages where he was tasked with fixing local community radios, one of the principle sources of communication and information dissemination in the region.

“The first primary school I remember going to was the Madrassa Taheria in Jamnagar,” Nafisa recounts, “it was a co-ed school, nothing like the idea of madrassas we have these days. I learned to swim and dance, and I was very good in gymnastics. I lived the life of a princess, encouraged by my mother to be bold and fearless.” As a Bohri Muslim from a family with royal lineage Nafisa's mother used to wear the rida (like the hijab), drove the family's Dodge car and often travelled with her husband to local villages, despite warnings from community members that this was not appropriate behaviour for women.

By the early 1960s the family came to Ahmedabad and Nafisa was sent to a Hindu majority school. She was not comfortable there and had few friends, not only because of her religion, but also because she was perceived to have come from a small town and did not speak the city lingo.

“My father was not happy in the government information department either. He was being harassed by his colleagues, and one day he overheard them say that if they had a gun they would shoot him. So my father began to live in fear, his health suffered, and my mother started to stitch and sell clothes for additional income. I used to help with the housework whenever I could.”

But her mother also wanted Nafisa to have quality education, like her older brother who had gone to study in Bombay. She approached Mt. Carmel, a convent school, to get Nafisa admitted. As there was no place in any of the Gujarati medium classes, Mother Bernard, the principal and later, a close mentor, insisted that Nafisa join the English medium class. Her mother was a little wary as Nafisa had always stood first and had never seen failure. While Nafisa continued to shine, it was during the communal riots of 1969 that she again realized what it meant to be a Muslim. Her best friend at school
came from a wealthy family and would have her car pick up and drop off Nafisa every day to and from school, a time together the young girls enjoyed very much. But after the riots Nafisa’s best friend was forbidden to interact with her, and to this day, despite having lived in the same city, Ahmedabad, they have not met.

“I wanted to be a doctor when I finished, but we could not afford it so my mother forced me to study nutrition at MSU, Baroda (Maharaja Sayajirao University). I developed kidney problems while I was at university, and I had to take a break. And, then because of my financial situation, I gave private tuitions.” She took seven years to complete her degree, and in the last semester, looking for a room to rent, Nafisa again realised what it meant to be a Muslim. She changed rooms eight times because no one wanted a Muslim tenant. It was during this time that Nafisa and Rajoo Barot met, both members of the university theatre group, and he became her life partner complementing her development work with his folk songs on water, plays on issues of justice and brilliant photography.

Facilitating Utthan

On her return to Ahmedabad in 1979, Nafisa joined the Ahmedabad Study Action Group (ASAG) as a nutritionist – recalling her first visit to villages in Dholka block (taluka) to talk to women about the importance of dietary diversity and eating green vegetables, she said, “The women looked at me, with my university degree, and just laughed. ‘We have no water for drinking, or cooking vegetables, our children are not going to school, what on earth are we going to do with your notions of good nutrition’, they asked”.

Deciding that she needed practical knowledge, Nafisa joined Penelope Lane, Padma Chougle, and Indu Mishra, colleagues at Ahemadabad Study Action Group (ASAG), who were completing a participatory planning exercise in another block, Dhandhuka taluka, in the coastal semi-arid Bhal region. Nafisa was invited to use her good communication skills to facilitate dialogues with the government and the four women gradually built rapport and trust amongst themselves. Influenced by Ravi Matthai’s Jawaja project on community centred processes of change and self-reliance in Rajasthan, the women decided that they needed to take forward the implementation of the plan they had worked on. They left ASAG in 1981 to form Utthan, which in Hindi means upliftment or rising.

The Bhal region, in coastal Gujarat, with its windy, bleak landscape, dotted with large areas of salt-pans, provided Nafisa with her real learning. This was a land of mirages, with not a drop to drink, describes Nafisa, recounting how they used to walk for 25 km a day with women, learning from them how they survived in such harsh conditions. In one of her first experiences of the brutality of water scarcity, Nafisa remembers seeing a little girl, extremely dehydrated, in the village of Jhandki - “I wanted to give her some OHT salts and asked the mother for a glass of water. She brought me half a glass of water which was turbid. I asked for more water, and again she brought me another small glass, and again...till women around me explained that this was from her drinking water quota for tomorrow. The girl never survived.”

Men looked at all the unproductive land and told the team that they needed employment, while women talked about the (drinking) water problem as the priority issue, which was leading to daily conflicts and migration. Besides stark gender inequality and violence, there was also the exploitative money-lending system run by the powerful upper castes, the Darbars, which was further crippling families. So, after several meetings Utthan identified local leaders and facilitated the formation of Mahiti (which means information), as an engine of change. Together, and through interaction with local communities, Utthan-Mahiti sought alternatives for making saline land productive, provided women with income generating opportunities through self-help groups, and looked for sustainable solutions for the water crisis. All this was accomplished through a process of empowerment, challenging patriarchy, feudalism and economic exploitation. Building on traditional knowledge and community management systems, Utthan-Mahiti facilitated the construction of lined village ponds in 20 'no-source' villages, to harvest and store water, primarily for drinking purposes. These ponds were lined with polyethylene sheets, which were obtained for free from Indo-Petrochemicals Limited. The plastic prevented the seepage of saline water, and the water collected was then passed through a slow sand filter before being distributed.

Apart from lined ponds, reverse osmosis and roof water harvesting, Utthan highlighted a number of
low-cost decentralised water solutions as an alternative to centralised planning which was largely focused on dams and the tapping of groundwater for delivery through long pipelines prone to leakage or forcibly broken. Not only did they have to mediate between engineers and local communities about location and design of various alternatives and their contributions, there were also differences between opinions of men and women within the community, sometimes from within the same household. By the mid-90s, as Mahiti became more independent with the committed leadership of a Dalit woman, a trained team, and the ability to raise its own funds, Utthan moved on to cover other parts of Gujarat – the coastal districts of Bhavnagar and Amreli, and the tribal areas of Dahod and Panchmahals in eastern Gujarat, addressing issues of natural resources management, access to safe water, sanitation, good governance and gender justice. The practice of purdah (seclusion) made it difficult for Utthan’s male staff (engineers) to talk to women, so a conscious effort was made to engage more women and to provide them with a gender sensitive and safe work environment, including transport to the field.

The communal violence of 2002 marked a watershed in Utthan’s work, encouraging it to focus more critically on questions of diversity within the organisation and on inclusion of minorities in its livelihood and peace-building programmes. Networks were formed with other civil society organisations in Gujarat (e.g. Citizens for Justice) and globally to address issues of conflict at all levels, from water and resource rights (women and land) to democratic values and human rights.

Accidental changes

In 1998, Nafisa faced a challenge that was going to transform her life forever. While returning from the field late one night, her car was hit by a truck and the head on collision left her with irreversible damage to her spinal cord, according to doctors in Ahmedabad and later Bombay, where she went for treatment.

“I was told that I will never be able to walk again, and that I should go to Birmingham for rehabilitation. Though friends helped, we had no money in our bank account, and then I declared that my rehab will happen where my heart is. So I tried parallel/ayurvedic medicine in Kottaakal, Kerala. At that time, my left arm was in a sling as my collarbone was broken, and I could not move either of my hands. From 1999, a year after my accident, I started to go to Kerala for a month each year and gradually with all the various massages, etc. I regained the use of my hands. Although I was still on a wheelchair, I never stopped working or travelling. I used to travel to the field and the team would carry me to see something or the other. But, it was when I went for meetings, in India or overseas, often on my own, that I realised what it meant to be ‘disabled’ or ‘a paraplegic’ as my doctors described me. Few buildings have any access or ramps, toilets are not constructed for people with disabilities – though this is changing slowly now in public places like airports.”

At the Water Supply and Sanitation Collaborative Council’s regional meeting in Bangkok in 2000, where the WASH needs of people with disability was first raised, I realised how our own work on social inclusion and gender had not been inclusive. Later, on a flight to The Hague for the 2nd World Water Forum (WWF), I was a victim myself of insensitive flight crew who did not allow me to keep my portable wheelchair on the flight with me. My legs were still not strong enough for walking on crutches so Rajoo, who was coming to perform at the WWF, had to carry me each time to the toilet. At The Hague, while there was a lot of talk on finding local solutions to water problems, there was little focus on people with disability.”

Over the past two decades Nafisa has learned to live with her physical challenges, raising awareness through a range of networks and advocacy platforms such as the Global Sanitation Fund and the South Asia Conference on Sanitation (SACOSAN) on the WASH priorities of people with disabilities, particularly vulnerable women, already marginalised by mainstream water discourses. She travelled to Kutch to advise on the design of homes from the perspective of women who had become paraplegic because of the massive earthquake of 2001.

With Wateraid India, she and fellow colleagues worked on a strategy for addressing the rights of the people with disabilities to WASH. Whether its taps inside toilets or the appropriate design of toilets, we need to look at all our WASH related infrastructure with this awareness of and sensitivity towards those who are physically challenged. But it’s not enough to just make training manuals, or put a handle on a toilet; we need to sensitize our decision-makers.

“There is so little recognition, or even funds, it’s as if...
our disabilities are invisible. When you look at other people suffering and surviving – I draw my inspiration from that; from my early years in the Bhal region, living on rotla and lassuni sabzi (flat bread and a dish made from garlic and red chillies), from the strength of my mother and how she stood up with dignity as a Muslim woman. Empowerment is a process of facilitating energy of other women, and in the process it empowers you too...and there are women stronger than me.”

In 2010, Nafisa was diagnosed with breast cancer and within a year she had had a double mastectomy. Last year (June 2016) she stepped down as the executive director of Utthan, but still continues to mentor the new leadership and is a part of the board (executive trustee)¹. “I want to travel, to visit new places and cultures without the tension of making presentations, to explore my creative talents in art and theatre, and to never stop learning,” she says in closing.

¹ Nafisa Barot is also an executive member of the Governing Board of SaciWATERs