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Walking Tall: Urmee Mazumdar

It was close to midnight when I clicked to clinch my friendship with Urmee Mazumdar (I never use her formal name Suchismita) on Facebook. She lives barely 10 minutes away from my home, and we have met on and off for close to two decades. Our conversations over the years have ranged from our children, our jobs, to our spouses. I even remember a particularly spooky ghost story she related one afternoon when she dropped into our Assam Tribune office to hand over some press release. Urmee is petite, small-boned, with beautiful dark eyes looking out of a chiseled face that almost always wears a solemn expression. Her voice is low and musical, with a throaty inflection that sort of gets to you. She had long hair once, but now she sports a stylish bob that gives her a girlish, pixie look. There is something very relaxing about Urmee's presence. It is as if she accepts you as you are, as if she is in no hurry to go anywhere, and I have to say this, she has never badmouthed anyone in all the years I have known her.

But how much do we know a person? Don't we often assume we know them well, only to discover after some incident that they are utter strangers? I have to get to know Urmee better because I have to write about her, get under her skin, reveal her brave struggle against a crippling disability, but I don't want a cardboard cut-out of a poster girl of the "differently abled" (the terms keep changing faster than you can remember). So here come the Facebook pictures: Urmee at a table, in a russet *kurta* and funky blue-framed glasses. Daughter Pakhi captions it, "My backbone! My *Ma*." There is a heart-shaped cake and a gleaming candle, marking the first wedding anniversary after the passing away of Urmee's husband Binoy. Mother–daughter duo share a great love for praline chocolates, carrot cake with cream, and Urmee writes, "It's my life and yours, live and let live, all will be happy in the end."

On the evening I go to meet her and sound her out on the idea of featuring her in this book, Urmee is in bed, even though it is only early evening. She has had a nasty fall and fractured her already weak leg. Propped up by large pillows, her leg in a cast right up to her thigh, she gives me a rueful smile and describes the incident with a shrug of her delicate shoulders. Her mother is in the room, to keep company. Urmee has books and files all around her, and the laptop close by. She cannot be still for a moment and in the soft glow of the bedside lamp, she is like an elfin trying to get away.

"I couldn't have chosen a worse time to fracture my leg," she grumbles. "There's my daughter's wedding coming up. I've had the caterers over to decide the menu. Pakhi wants it to be just right. And then the trousseau, I must get the *mekhela chador*s from Sualkuchi." She glances at her husband Benoy's photograph framed on a side table.

"He left us so soon . . . and I have to do all this alone." A shadow flits across her face, but soon she is urging me to partake of some sizzling hot home-made snacks and cups of cinnamon-flavored tea. She listens to my book proposal, nodding, her face alive with anticipation. Of course she would share with me her life's story—struggling against great odds, endlessly overcoming her limitations, putting on a brave face, challenging fate, and finally inspiring and helping others like her.

Pakhi's wedding, at the sprawling Gymkhana Club in Guwahati, is a glittering affair. As the guests mingle and congratulate the couple, there is admiration for Urmee, the single mother, who has overcome her bereavement and the accident to make sure that everything is just right.

Finally, she has time to turn back the pages of her life's book and go back to the very beginning.

"I am the eldest of the four siblings who grew up in a pretty house called Reff House, which belonged to my father, late Kripa Nath Dutta and mother Smt Mondira Dutta. The house stood on a tiny hillock on Kench's Trace, beyond Laban, in Shillong. My two younger brothers, Partha and Siddhartha (Geetartha was yet to be born), went to Sishu Mandir School in Bishnupur. I missed a year due to my illness, and so my brother Partha, the older one, and I were in the same class. It was an English-medium school, and our friendly Bogi Miss, the headmistress, was a kind woman who made us feel wonderful. I was average in my lessons but loved to recite nursery rhymes with action, as taught by our head teacher. My brothers and I were the best buddies. We had the same friends in our neighborhood, and after school we got together for some fun. Because I could not walk properly, my brothers and friends thoughtfully included me in playing marbles, crawling games, *gilly danda* (a game), ludo, hide and seek, and acting out drama skits. I was never sidelined and made to feel sorry for myself. Nobody commented on my handicap. Maybe that is the reason why I have always believed myself to be equal to everybody else and not claimed any privileges."

"When did your parents seek medical help for you?" I ask.

"Well," she continues. "I was just one and a half years old when I suffered from a persistent high fever for several days. The homeopathic medicines could arrest the fever for a few hours and the onset thereafter scared my parents. They contacted my mother's relative, Dr Bhubaneswar Barua, who asked them to bring me immediately to Guwahati. The doctor was shocked to discover that I had polio, a rare disease at that time, and the vaccine for it had not been introduced in our country. By the time the treatment started, the right side of my body was already losing all sensation. The doctor stationed himself at my grandfather's house at Jorpukhuri and for three days and nights pushed injections one after the other to arrest total paralysis of the right side of my body. After a long ordeal, he could save only the upper part of the body and the upper limbs. The whole of the right lower limb was totally paralyzed. My family was devastated. But my parents were practical enough to start me on physiotherapy and messages once we got back to Shillong."

"Then, when I turned 13 my father told me that an orthopedic surgeon from England, Dr Bolin Gogoi, was coming to Guwahati to help children with polio by performing corrective surgery on them. We had just migrated to Guwahati after shifting of the Assam capital due to the creation of Meghalaya as a separate state. My brother and I went to St. Mary's Convent. We lived in the new house my father built at Silpukhuri. Father's words gave me some hope. I was beginning to tire of walking to and from school with my right leg dragging after me."

"When I met Dr Gogoi with my parents, I begged him to make my leg strong, so that I could walk for miles and miles without tiring. 'Don't worry,' he told me cheerfully, 'you will be able to run around and even play lawn tennis if you like.' Finally, the three-phase surgery started at Guwahati Medical College. Dr Gogoi conducted muscle transplantation from inner thigh to knee, strengthened my calf muscles, and tended to the feet tendons. I was in hospital for six months and never complained for a second. There were visitors throughout the day and my brother brought so many Junior Classic comics that they piled up and became a side table at my bedside. Since the hospital was located in Pan Bazar, a commercial place, I could ask for coca-cola and ice-cream at any time. Seeing me treated like a queen, with my every wish being fulfilled, my youngest brother Gitu said he wished he too had polio like me. We all had a big laugh over that. After some tough physiotherapy, I was finally released from the hospital. I still had a limp, but my leg was stronger and I could run. Back home, my carelessness caused fresh trouble. I walked over a plank on a rain-filled read and slipped, twisting my operated knee. The pain was excruciating, and my parents were furious that I had not been more careful. My father called up the doctor, who assured us that there was no fracture, but that only a bit of the surgery had come undone. I was asked to rest for 21 days before a final assessment could be made. As a result of this I could walk but was unable to run. So, no lawn tennis for me. But I did not brood for long. I had learnt to accept whatever I got in life and my needs were very simple."

"So how was it to feel you were different from others?"

"My youngest brother arrived soon after my recovery from Polio and I had a companion to play with. My mother was busy with him so I was looked after by my father and an *ayah* (maid). When I was four years old, I realized something was amiss, because whereas my younger brother could walk around to get his toys, I could barely stand without support. I was his older sister, his ba, but it was he who was walking, while I was crawling. My other brothers also did the same. There were times when I threw tantrums because it was so frustrating to be like that. But by and by, my brothers gathered around me to listen to my stories. They, my cousins, and friends involved me in all their games, and I felt loved and needed. I would often bruise my knees by trying to run like them, and it bothered me a lot. My parents told me it was a dreadful disease but that I would get better when I grew older."

"Sometimes my brothers would initiate my walk, and my father would explain how we were all different, with different traits and abilities: 'See, Partha is so fat he can hardly climb trees, whereas

Siddhartha has a sharp nose to sniff out trouble, and Gitartha was so thin and dark as a baby. How different you all are. It doesn't matter how Urmee walks, as long as the job is done. Is that clear?'"

"So what if I could not run? In the years to come, my brothers and I were as thick as thieves, getting rid of a tutor whose teaching we did not like. We bunked guitar classes on Sundays to go to morning shows. I used to compose letters for Partha to give to his girlfriends. Partha in turn would bring letters addressed to me from his friend Binoy (who later became my husband). Binoy came to me one day with an enormous pair of goggles. He shyly told me he did not know how to talk to a girl but that he wanted to be my boyfriend. I had this big jolly gang of brothers and cousins and did not much care for an exclusive relationship. "Let's be just friends," I suggested. So in many ways, I was enjoying a normal life and had the vanity of a normal teenager. I was very proud of my waist-long hair and threatened to stop going to school if my father cropped it in a pageboy style."

"In the 1970s and 1980s, any form of disability was seen as a curse. Families would be torn apart with shame and wallow in self-pity. People would gossip and give unsolicited advice. A child had to endure the double burden of his or her handicap and guilt about the suffering he or she is causing to the family. Often the mother was the one who was blamed for the affliction. Things were, of course, much worse in the villages. The disabled person was often neglected and subject to emotional abuse because he or she was not a productive member of the family. That was not all. They were often lodged in barns and outhouses and served meals there, as if they were animals. No wonder, many of them could not survive for long. The discrimination and abuse stemmed from the fact that a disabled person could not earn an income. That is why, as a disability activist, I lay stress on skills training for disabled youths above 18 years. There have been instances when young women have deliberately chosen to marry disabled youth because they are skilled artisans and earning a comfortable income through their micro-enterprises."

"As a young girl, I had to listen to an aunt stating bluntly that I would never be able to get married because no boy would propose to me. Later I found out that only two percent of people with disabilities (PWDs) were able to lead a conjugal life. Even my in-laws made discreet enquiries before the wedding if my illness would be passed onto our children. My enraged father almost called off the wedding."

"But things are much better today, thanks to the United Nations Convention on the Rights of Persons With Disabilities (UNCRPD) Act for recognizing the fundamental rights of persons with disabilities and ratification of the act by many countries, including India. The Government of India, slumbering with the People With Disabilities (PWD) Act, was finally asked to implement the UNCRPD in all the departments of the government, by which the disability sector has gained access to all welfare schemes. Persons with disabilities now have equal rights to education, health, livelihood, and social recognition for their individual achievements. It is a slow process but, nevertheless, it is happening, thanks to the social activists, NGOs, and general well-wishers all over the world."

Urmee pauses and takes a sip from a glass of water by her table. "You must understand that a big milestone was achieved by the UNCRPD, which so many countries ratified, and this law demands equal fundamental rights for these marginalized citizens. The fallout of UNCRPD is great for us, as it has also the penal obligation which binds everyone toward non-discrimination of disabled persons at all levels. This convention focuses more on children with disabilities, women with disabilities and severe or multiple disabilities. The PWD Act 1995 did not have this panel component, and hence, its implementation by the government was nil."

"Let's get back to you." I suggested gently. "Do you lapse into self-pity? Or is it true that you push yourself in order to prove you can in fact achieve more than people without disabilities?"

"My upbringing has been such that there has been no room for self-pity. Like my father, I understood the value of developing a work culture. After my graduation with English honors, father set about preparing to enroll me in postgraduate classes, but I put my foot down, as I was determined to find a job and become independent. Further, I did not want to do my MA, as I knew I could not shine academically. I could write the answers very slowly and so had to leave the answer scripts incomplete. I also did not much fancy a lecturers' job, which was often the only option for Arts graduates those days. My dear friends Ashok and Rubi Barpujari then arranged for me to appear for an interview held by the Divisional Manager of Usha International (then Usha Sales Limited) and I came out in flying colors. I joined as a Commercial Assistant in Usha with a six-month in-service training period. So armed with a diary, I entered the corporate world, jotting down indents, invoices, and delivery of fans, sewing machines, diesel pumps, and piston rings to Usha dealers all over the Northeast. Slowly I made myself so indispensable that my boss depended on me for the smallest details at the public and coordination department. He, Mr Bindra, often praised me and coaxed me to join the Usha Sales Ltd. office at Ernakulam. I was proud and happy when I got my first salary. I promptly bought a tape-recorder and offered my parents to pay the wages of our cook Raghu and meet other expenses. I felt really proud when they agreed. But this lasted for only two years. In 1981, I got married and moved to remote tea estate in High Range Munnar, Pullivasal, where Binoy worked for Tata Tea Ltd. I became just a housewife, and all I had to do was to cook and keep our home spic and span. But then, unknown to me, my shift from the corporate to the social welfare field would begin from there. The ladies of High Range offered me an honorary job of looking after the crèches and rehabilitation work in the tea estates. Once again I was back in action and loving it. Binoy was also very proud when I gave my feedback to all the Senior Managers every Saturday at the High Range club. The people there were very curious to know about the headhunters, the practice of paying bride price, and even the reason why we had mongoloid features. I answered them as best as I could and they were entranced by the *mekhela chador*s I wore to the club meets. One day some tea pickers even asked me how many buffalos Binoy sir got to marry a poor, disabled girl like me. I stretched my hands and replied, 'Lots, he got lots.' When the manager heard about it, he wanted to reprimand the women, but I pacified him, saying it would take years to sensitize them about disability. I was also learning Tamil and my interactions with the laborers helped me pick it up more easily."

"Then I got pregnant and my parents were over the moon. In fact my father wept when I first told him on the phone. I came back to Guwahati and was spoilt rotten. I had always been 47 kgs and now I gained 10 kgs. My mother cooked me delicious meals, and I polished off everything double quick. My mother-in-law sent me cream and *rasagolla*s from North Lakhimpur, and my father-in-law sent a huge rahu fish every now and then. My mother-in-law came once and not only slept by my side, but woke me up early morning for a walk. I hated getting out of bed, but the walks helped me to remain fit. Finally, on the auspicious day of Bijoya Dashami—on October 19, 1982, my son was born. As I held his tiny body in my arms, I realized that I was indeed blessed."

But Urmee had more, so much more to give to the world. Being a wife, and then a mother, was simply not enough for her. There was a spark in her that made her want to push her limits. This time she had in-service training at Sishu Sarothi, the Institute of Cerebral Palsy, Assam, and after a series of training programs outside Assam, she earned a license as a Rehabilitation Personnel from the Rehabilitation Council of India, New Delhi. With the help of her sister-in-law, Arzoo Dutta, she had the good fortune of meeting social activist, late Sanjay Ghosh, who briefed her on the process of starting work on disability in the rural areas where there was a crying need for such intervention. Binoy also believed that seminars on disability in air-conditioned city halls would never be able to address the needs of the disabled in rural areas.

Thus was born Urmee's dream, Swabalambi (self-reliant), a community-based organization facilitating services to more than 700 disabled persons in the rural areas of Dimoria block, Kamrup district (metro), which started its work in 1997 with three special educators doing the basic survey with the help of field workers of World Vision, which even provided a space in their office at Sonapur. There were many people with deformities, who were a big burden to their families. Besides describing them as *bemari* (illness), nothing was done to help them cope with life and become productive members of the community. So World Vision spread the word that these *bemari* people and their families could come for counseling held by Swablambi at their office every week. Soon Urmee and her colleagues had their hands full, with people flooding to their center. It was soon evident that none of the disabled were ever taken to a doctor for assessment and therapy. Families were wary of coming to the city for treatment and had no intention of spending their hard-earned money in seeking a cure. Till the parents were alive, the disabled had a roof over their heads and three meals a day. There had been a series of deaths, all of disabled persons, in the area, underscoring how bleak the situation was.

"After we came to know about the fate of the disabled in the villages, I was haunted by the thought that I should have started this work earlier. Without wasting a moment, I began Swablambi's preliminary work, which was to convince the villagers that disability was not a disease and that was why it could not be cured. We started health camps, and doctors of different departments of the Guwahati Medical College and Hospital came as volunteers to clear misconceptions and change mindsets. As the patients were examined, we found that a lot of them required corrective surgery.

A boy with a severe ear infection needed to be operated, and a boy who moved in the kneeling position with the help of a bamboo pole had to have his knees rectified by surgery. We offered help to people with cleft palates, including a patient who had complicated hip surgery. We offered therapy to children with cerebral palsy. We taught them that mentally retarded people needed to pick up self-help skills of cleaning, eating, and grooming."

"But believe me, it was not easy. These simple, unlettered village folk were fearful at the prospect of surgery, of letting their dear ones be 'cut open' as they said, by doctors. What if the illness was still not cured, or if the patient died on the operating table? It took us a while to convince the people that we were not playing with their lives, that the surgeries had a high success rate and would reduce their disabilities. I told them that I myself had gone through seven major surgeries for my polio, that too at a very young age."

After two months, families with patients entered the Guwahati Medical College and Hospital. Urmee and her team were at hand to guide them through the bewildering maze of wards, corridors, and wings, do the necessary paperwork, boost their morale, and attend to the smallest detail. There were people who often got lost in the vast complex and were close to tears.

"From 1997 to 2002, we were busy identifying all categories of disabilities in the 12 *gaon* (village) *panchayat*s of Dimoria Block. There were just a few of us and very little money to go around, but the thought that we could make a difference in their lives motivated us to work hard. After three years of work we got grants from the Ministry of Science and Technology and Ministry of Social Justice and Empowerment, New Delhi. We were now able to recruit local youth as resource persons to train the disabled youth in skills and trades that are viable in the market. We offered special education for children with disabilities, integrated children in primary schools, ensured health care and corrective surgeries. As the years passed, we became like a family, our lives interlinked, as we shared all our joys and sorrows. Now Swabalambi is affectionately named as Bikalanga office and our staff as Bikalanga doctors. There were sponsors for the corrective surgeries, and they met with the families of patients. They include Guwahati Refinery, Oil and Natural Gas Corporation (ONGC), Numaligarh Refinery, and many others. Funding from CARITAS India has upgraded the status of the organization as an established community-based organization utilizing foreign funds to carry on activities involving the *gaon panchayat*s, the Development Block, government officials of the block, government teachers, Integrated Child Development Services (ICDS) officials and so on in the rehabilitation program for persons with disabilities and mainstreaming them. We have also collaborated with VAANI, the deaf children's foundation in Kolkata. I have myself been a trainer with VAANI's Brinda Krishna. With their help, we have worked to develop cognitive ability and total communication with families, peers, and the community. Our workers are trained in the Indian Sign Language and vocabulary for the deaf. As a result, many deaf children have broken out of social isolation."

"If there is one goal that I long to achieve, it is that Swabalambi becomes a recognized resource center on all categories of disabilities in Assam in the near future."

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It is a bright, sunny April morning when we arrive at Swabalambi's main community center at Mohmara Road in Sonapur, near the Forest Range Office. Started in 1977, it encompasses 120 villages in the Dimoria Block and covers 12 *gaon* (village) *panchayat*s. It is based on community-based rehabilitation (CBR) where Disable Persons Organizations (DPOs) are deployed to identify the disabled people in their own communities and bring them to Swabalambi to help in their empowerment. Earlier, workers and helpers of Swabalambi used to carry out this process. But now, with the setting up of Community-Based Rehabilitation Program, which is a highly scientific and decentralized method of penetrating interior areas, disabled volunteers work for the improvement of their kind. This has been established as an effective way, especially because it is also very transparent. As the level of awareness has increased, PWDs are demanding their rights and the benefits to which they are entitled.

Urmee and her band of helpers cope with numerous difficulties, big and small, in their day-to-day work. Their Sonapur office suffered extensive damage during two violent storms. In 2005, a fierce gale blew away the roof, which had to be built again.

There are other difficulties that slow down their work. To ensure that all PWDs are provided with the requisite help, DPOs are deployed to identify them. Then they are taken to Mahendra Mohan Chowdhury Hospital at Pan Bazar, Guwahati, where they are examined by a qualified doctor. Then they are issued an identity card that they must produce in order to avail of all benefits given by the government in different schemes.

"But unfortunately," says Urmee, "there are no special funds provided by the government. There is instead, a Disability Pension, which is ₹6,000 per year and is indeed a pittance." The most glaring example of the government's apathy can be understood by the lack of utility services for PWDs in most public places. They are not extended free travel benefits. Children with mental retardation who are below 14 years of age are given a measly ₹500 per month. The same amount of money is payable under the unemployed pension for PWDs above 18 years of age. School-going children with disabilities are given ₹1,500 every six months. We at Swabalambi work hard to provide corrective surgery and have enabled 3,000 cleft-lip operations. We also provide hearing aid, wheel chairs, and tricycles. Pharmaceutical companies and organizations like Shankar Nethralaya undertake programs where cataract operations and other services are offered.

Our commitment to persons with disabilities is total. After proper counseling we try our best to ensure that they lead normal, productive lives. Once the degree of their disability is assessed, they are trained in various fields so that they are integrated in society and can earn their own livelihood. The family members, teachers, and friends of PWDs are also trained so that they can help them.

At Swabalambi, men usually engage in jute, bamboo craft, screen printing, operating Xerox machines, photography, piggery, candle making and so on, while the womenfolk engage in embroidery, stuffed toy making, cutting and stitching, weaving, fruit preserving, and all local trades. The objects they make are displayed and sold at various expos and fairs.

In many ways, Urmee is the benevolent but exacting matriarch who presides over her family with quiet authority and gentleness. She recently organized a grand wedding for the two lovebirds, Jogesh Rahang and Nilima, who now look after the center at Sonapur. Both suffer from cerebral palsy, but Jogesh excels in making jute products. There are in total 15 salaried employees to help the disabled. Among them is Bipin Das who has palsy in his right hand. He is a CBR worker and a trainer for deaf children. He has been with the center since its formative years and he specializes in bamboo craft.

Then there is Rita Deka, who is a DPO leader. She has locomotor disability on one side but has won laurels in swimming and basketball. At one time she was unable to look after herself, but now she can even help others, thanks to Swabalambi. While Rumi is a coordinator of deaf children, Runu Gogoi is an Indian Sign Language (ISL) trainer.

Swabalambi teems with brave, hardworking people with many inspirational stories. "Take the case of Sunita Nayar," says Urmee, "her parents were so disappointed when she was born that once on a boat trip on the Brahmaputra, her father advised her mother to throw her into the river. But she has overcome most of her locomotor disability to become the vice-president of the DPOs."

That afternoon we attended a meeting attended by PWDs, the newly elected *panchayat* members, and Swabalambi workers. There is animated discussion on *panchayat* schemes for social development, BPL cards for PWDs, and disability pensions. Several spoke out about the government not providing funds and anomalies suffered by persons with various disabilities. Volunteers moved about serving food with care.

The UNCRPD Act has undertaken the obligation to ensure and promote the full realization of all human rights and fundamental freedom for persons with disabilities without any discrimination. Urmee and her team undertook the task of translating this act into the vernacular language and have organized workshops and raised public awareness of disability rights. In the Census of 2001, it was estimated that the record of disability was just 2 percent and so there was a very meager budget allocated for the disability sector. Urmee got to work, with her enumerators fanning out in all directions to gather the correct estimate. So the accurate figures were included in the 2011 Census, leading to more effective policy and increase in budget allocation.

Helping afflicted villagers to avail of medical aid was a turning point for Swabalambi. Urmee and her team formed a wonderful rapport with the villagers. Till today Swabalambi has been able to identify and treat 700 disabled people. They have also linked up with other agencies that provide artificial limbs, hearing aids, crutches, wheelchairs, tricycles, and other equipment. Arming them with a trade helps them to be self-dependent. So Urmee's training center was born. Children and adolescents with disability are trained for pre-vocational and vocational skills needed to design clothes and make bamboo cane and jute artifacts. They sent raw materials, identify shapes and sizes, choose colors, and learn the concepts of time and money. Urmee is careful to allot tasks according to individual capacity. Only those with moderate-to-mild disability are involved in more intricate cane, bamboo, and jute craft, weaving in handlooms, tailoring, machine embroidering, and so on. Their products have been displayed and sold in various exhibitions, International Trade Fair, and Fabindia. Urmee has also worked hard to create products that are likely to appeal to a discerning clientele, like bread baskets, fruit baskets, and so on. Many of the workers are primary earners of their families.

Every weekend, students, doctors, and well-wishers visit Swabalambi's office at Sonapur. They share a meal with the disabled youth and appreciate their skills. Many among these youth have won medals in the Abilympics (Olympics of Abilities of Persons With Disabilities) held in New Delhi every year.

The little girl who dragged her limp leg behind her as she struggled to keep pace with her playmates is today a source of strength and support to countless others similarly afflicted. Urmee is upbeat about the future, refuses to dwell on her frailties, and dreamily sums it all up. "As I look back on my life, I feel what I have desired the most is to be more than what I am at a certain moment. I have always fought against pettiness and idleness. Every day I seek to expand my boundaries—to feel more, learn more. I am always wanting to grow, improve, expand. And it is this which always fills me with energy and hope. And in spite of everything, I feel truly blessed."