



**The sublime, indomitable spirit of an unsung few who have risen above their disability**

By **PRITHA SEN**

I would call them survival stories, not success stories," says Preeti Monga, 39, taking a break from signing a sheaf of official letters a colleague has thrust at her at the last moment. Tall with striking good looks, she's manager, marketing and resource development, at Katha, a

Delhi-based non-profit organisation dealing in creative communication. The last of the initials taken care of, Preeti pushes back her chair, looks you straight in the eyes and says, "Let's go". On the way she talks animatedly about her work at Katha, where she develops materials such as letters, brochures etc, conducts sensitisation campaigns in public schools on topics of social concern and

# Trying to Grow

***This cerebral palsy victim has a masters in social work. Her dream: a thesis on 'marriage between disabled and non-disabled people'.***

liaises with the corporate sector for financial and material support for Katha's projects. All the while directing the taxi perfectly through the long drive to her trans-Yamuna home from her office in south Delhi. It's only when she has to cross the road to her apartment that she asks for a little assistance. Preeti is blind, a small-pox vaccine having damaged her optic nerves when she was 21 days old.

Preeti does not wear her disability on her sleeves. "Why should I? I don't board a bus through the roof or drink tea with my ears. I'm like everybody else. It's just something I can't do—see. My brother, at 35, still can't serve tea without spilling half of it into the saucer," she giggles.

But how many find their place in society like Preeti has? Ten per cent of India's population is disabled—the numb-

ers a whopping 90 million, with physical, sensory or mental impairments. And every tenth person in India knows, at some personal cost, the meaning of exclusion, discrimination and humiliation. Attitudes which group them as oddities and deny them their right to a dignified existence. Indian society accords them no place within its ranks—they are kept in the shadows, hovering in a twilight zone. Failing to understand that the fault does not lie with them.

Then again, breaking free of these shackles, some have risen, achieving soaring heights. But for every Satish Gujral, Firdaus Kanga and Sudha Chandran, there are thousands others striving to lift themselves out of quagmires of silence, sightlessness and solitude. Individuals in their own right, unsung heroes who mould their future to suit themselves. Creating history with their stories. Not of isolation but of integration. Refusing to bow to preconceived notions of a society decidedly uncomfortable with the word disability.

"The greatest disability is doing no work," says Chandigarh's wonderman Vineet Khanna. Founder-director of the Youth Technical Training Society (YTTTS), one of the most successful NGOs operating in Punjab, Haryana, Himachal Pradesh and Chandigarh, the 46-year-old zips around in his specially-equipped Tata Sumo, travelling flat on his back. For Vineet has been immobile, neck down, since age 20. After a minor accident, doctors put him in a body cast which left him paralysed when it was removed.

**B**UT today, his days are too short as he packs into 24 hours supervision of vocational centres for youth; Pustak, a literacy programme for slum children; Vama, an empowerment programme for women; clinics, AIDS awareness campaigns and sanitation programmes—travelling to each centre including the areas of operation in the other states as well. Confined to a two-tiered stretcher, his wasted body lies at an awkward angle, his left leg resting on the second tier of the mobile bed—the kind of person who raises more questions than providing answers.

All this, while suffering from severe Ankylosing spondylitis, kidney problems and the after-effects of a stroke he suffered in late 1996. Has society rejected him? He's the most respected man in Chandigarh today.

"Society treats you the way your family treats you. My family let me fall, get hurt but in the end I learnt to stand up and look straight ahead," says Preeti. Jeeja Ghosh does not quite agree. "The one thing, the only one thing that bugs me," says Jeeja, sitting in her windswept eighth-floor south Calcutta apartment, "is the social barrier I continue to face, the jibes, the sanctimonious sympathies, the stares on the roads." That's what pains her most, not her body, which has refused to obey

commands ever since she was born with cerebral palsy.

Like when doctors at hospitals harass her during her visits for a disability form—"A passport size picture (of Jeeja) will not do" a doctor says. "I need a picture of her naked to ascertain her disability." "In a bus they'll call me a mad woman or exclaim, 'how did her mother let her go out alone?' Tell me, what's their problem?"

Their problem, as explained by Prof. Ali Baquer, who heads the

#### **Preeti Monga**

**A small pox vaccine left her blind, but this 39-year-old works with NGO Katha as manager, marketing, and is a tireless votary of integration.**



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#### **Naresh Sharma**

**Polio didn't stop him from choosing shooting as a vocation. He's won nine medals and wants to outshine Jaspal Rana.**



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Delhi-based advocacy organisation for the disabled, Concerned Action Now, is 'frame of mind'. Uniformed condescension contributes to marginalisation of the disabled, according to Baquer. He calls the entrenched attitude 'disablism', which he sees as a "social construct and a flaw in the thinking processes of society." What is required is enlightenment. The Persons With Disabilities (Equal

Opportunities, Protection of Rights and Full Participation) Act, 1995, was a landmark ruling. It treats disability as a civil rights rather than a health and welfare issue. "Promotion of the Act is required," says Baquer and the disabled should come forward and demand their due. Agrees 24-year-old Priyesh Jain of Bombay who's been blind since birth. "I realised long ago it was my

duty to help people change their opinion about me."

Jeeja, whether she knows it or not, has taken not a step but a stride in the right direction. One of the first graduates from the Spastic Society of Eastern India, this pretty waif-like 29-year-old passed her ICSE examination and high school with flying colours, majored in Sociology from Calcutta's famed Presidency College, picked up a masters in social work from Delhi University, travelled to England for a two-month self-advocacy programme. All this at a time when there is still little awareness about cerebral palsy. These days she works as a professional social worker with the Spastic Society and plans to do her doctoral dissertation on 'marriage between disabled and non-disabled people'.

**Tamanna Chona**

**Born with cerebral palsy, she has an offer to study travel in Japan. Crazy about Shah Rukh and rap, she is now training in Manipuri dance.**

And slowly, others are filtering in to carve out their own little niches. Each fired by a zeal which spells hope to the next in line. The unifying factor: the need to be somebody, the need to grow on one's own steam, not on pity or charity.

Twenty-five year-old Kanchan Gaba (*see cover*) treks to the sub-zero Himalayan temperatures of Dzungri at 14,000 ft in her manic pursuit of adventure. She climbs, crosses rivers, throws a mean discus and hurls a javelin with fair ease, navigates car rallies and completes an adventure course conducted by the Himalayan Mountaineering Institute in Darjeeling. She fumbles for grip, hanging by rope a few feet above the ground, her fingers red and sore, the pain evident on her face. And then she tells her instructors: "Hey, let's do this again. Can't we? One more time. Please..."

**T**HE light went out in Kanchan's world when she was nine. "Retinal detachment" the doctors pronounced but "I was too small to understand," she says. "So I never felt unfortunate." Daughter of a Calcutta-based transporter, she went to the prestigious Lady Brabourne College. Now she's working towards a law degree and a bachelor's in Sociology because she's in a hurry to become India's first disabled civil service officer. Her crowning glory: when she was picked up as the only blind member of the 700-strong International Scouts and Guides camp in England last year.

The tide is turning, and there might well come a time when the trickle will become a flood. But that is not to say that for each of them the first few steps up the ladder of success was not a struggle. "I was the first person to say no," admits Narayan Singh Rana, Jaspal Rana's father, of Delhi's ace pistol shooter Naresh Kr Sharma. Stricken with polio three months after birth, Naresh chose shooting as his vocation, a rather expensive one at that considering his father could barely afford it. His job as a driver and guide with Sita World Travel did not pay enough to support the Rs 2,000-3,000 a month sport. But he did not stop his son. Ignoring cruel jibes, at 26, Naresh has participated in eight world championships and won nine medals, including two silvers and five bronzes. He's on his way to the World Shooting Championships in Spain, the run-up to the Para Olympics 2000. "I'm



T. NARAYAN

sure to win a medal there. I want to set a record of winning a gold."

Sporting a trendy pony-tail, the youngster wastes no time over his disability. He drags himself around on crutches and practises for a good nine hours every day at Delhi's Dr Karni Singh Shooting Ranges in Tughlakabad. Unable to stand, he perches on a high stool awkwardly, a handicap in itself. His only regret: corporate and government establishments don't have quotas for handicapped sportspeople. "It's so unfair. And it's becoming difficult to support my game without a job."

Samir Ghosh, deputy divisional manager, occupational health services, Tata Steel, couldn't agree more. He narrates a story of how when a friend wrote on his behalf to the Administrative Staff College in Bombay years ago inquiring whether Ghosh could sit for the civil service examinations, the answer was no, because he wouldn't be "able to ride a horse"!

Well, says Ghosh, "I'm yet to see an IAS officer who rides a horse to work." But Ghosh himself has galloped away with the laurels.

Thirty years ago, Ghosh literally rose again from the ashes. The then eight-year-old boy touched a 11,000 volt high tension wire while playing football. His charred hands had to be amputated. "I don't miss them any more, I've forgotten about them." A BA in English Literature was followed by a masters in welfare administration at Bombay's Tata Institute of Social Sciences. Then he picked up another masters in social planning from the London School of Economics. After working for a year with the UNDP, he joined Tata Steel, going on to set up the steel giant's occupational health services department. Happily married to Anagha, the couple have two daughters growing up in their Jamshedpur home.

But, then, as many would point out, Ghosh had the advantage of a privileged education. Not all are so lucky, concedes Preeti, admit-

**Raju Tiwari**

**He couldn't hear or speak but took up the family profession of a pujari on the ghats of Benares.**

**His devotion has helped him retain the family clientele.**



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ting to her upper middle-class background. "I was also lucky because in each of the organisations I have worked I knew the employer. When I joined the National Association for the Blind (NAB), I realised for the first time that everybody did not have as good a time as I did." The complete nonchalance with which she treats her handicap makes it easy to talk to her. At 26, two children and a bad marriage saw her become the first visually impaired aerobics instructor. On the way she picked up numerous honours for work in the field of the visually challenged including the Manav Sewa award in memory of Rajiv Gandhi and the 1995 Rotary Voluntary Service award jointly with writer Geetha Dharmarajan. Computer literate, she's worked in two marketing companies, creating markets in Bombay, Patiala, Chandigarh and Delhi, each time turning their fortunes around, before taking her present job.

**M**ARRIED now to a former colleague, Preeti still has a dream. "To start a project with senior school children, sensitising them to the needs of the disabled. For the disabled don't need special schools. They need to interact, to learn, to know what the outer world is all about to be able to lead normal lives. Otherwise you create barriers and oddities. In fact, I resent being written about. But then I think, just like a long time ago I received inspiration from a rather badly made TV programme called *Aur Bhi Hai Rahen*, someone else may receive courage from my story."

Integration is the key word, and those who have achieved have been helped in part by their circumstances, in part by those they have come in touch with but finally and most importantly by their desire to be just another faceless person in the crowd. In the process they have survived and come out on top.

In some there has been the intense desire to be in tune with the times. Like Priyesh Jain, who made a film because "today written things don't matter. You have to create on screen to reach across." He 'visualised' every frame of his 50-minute tele-film *Roshni*, about nuclear weaponisation. A gold medallist in economics and political science, Priyesh has an LLB to boot.

When he first went to see *Damini* with girlfriend Srividya, she kept up a continuous commentary, so that Jain sensed, not just the sound resounding off the screen but also the glitz typical of Bollywood. This experience was replicated in everything—decid-

### Vineet Khanna

**Immobile neck down, this 46-year-old, a writer and poet, has launched several NGO programmes. The most precious thing in his life? Daughter Diksha.**

ing on moonlight as the perfect backdrop for Shot One. Or that the beautiful girl initially chosen as the lead just did not "have the sparkle on her face". No wonder when he walks away sporting blue glares, even friends speculate if he is pulling a fast one. "They can't believe I'm blind."

It's a two-way process. Educating and sensitising society and creating a one-to-one interaction between the physically fit and the physically challenged. Social graces play a strong role, points out Preeti. She had taken up an innovative project, experimenting with the mobility of visually impaired children. "Their reactions are unnatural. A blind person will look everywhere else but at you when he's talking. That's uncomfortable," she says.

"I couldn't agree more," says Premila Lewis. Her niece Radhika Chand, 26, is a victim of Down's Syndrome but a winner all the way. Daughter of

### Malathi Holla

**Twenty-five operations to cure polio Arjuna award winner has won an inc lifting and discus throw.**

Indeera and Ramesh Chand of Delhi, Radhika's story touched thousands when Indeera came out with her book *Climb Every Mountain* on the trials and triumphs of bringing up Radhika. Born 26 years ago with Down's Syndrome, a condition marked by mongolism, retardation and lack of coordination, Radhika has overcome the danger of degenerating into a vegetable by constantly stoking her survival instincts. "My sister and entire family made sure that she was socially acceptable, that people did not recoil in her presence."

She's emerged a talented artist with a rare gift that eclipses everything that is not quite right with her. She's held solo exhibitions in oils, water colour and acrylic. Says artist Anjolie Ela Menon: "She has the characteristics of a true expressionist painter and her work, far from expressing her disability, bears out the well-known fact that sometimes in such cases a superior talent manifests itself." Says Radhika: "So what if I could not study? I can sell my paintings. I can also teach small children."

She's as good as her word. How many Down's Syndrome children have you heard of with a job? Well, Radhika does. She works as a teacher's assistant at Delhi's upmarket Vasant Valley School. According to her aunt Premila, Radhika's committed to her work. Says her grandmother Usha Lal: "She now sees herself as an independent young lady and not as someone who's disabled."

Neither does Tamanna Chona, born with cerebral palsy, who's just appeared for her plus two exams under the Open School. Daughter of Shyama Chona, principal, Delhi Public School,



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