Quest for Empowerment Gathers Pace

India's vice president addresses second national conference of affected persons

On October 4, India's vice president told a national gathering of people affected by leprosy in Delhi that there is a need to make a sustained effort to change the social image of leprosy. While praising India's achievement of leprosy elimination, he said, "We cannot remain oblivious to the problems of social stigma and discrimination, which force the leprosy-cured persons to spend their lives in exclusion, loneliness and ignominy."

"With a view to sensitize people to treat cured persons with love, dignity and empathy, we need to educate people that leprosy is not an easily communicable disease and clear their misgivings," Vice President Bhairon Singh Shekhawat told the 2nd National Conference on Integration & Empowerment of People Affected by Leprosy.

Organized by the National Forum of People Affected by Leprosy, the conference brought together 700 delegates from 14 different Indian states to discuss key issues such as housing, education and employment.

India's constitution, the vice president reminded delegates, "provided us not only a right to live but a right to live with dignity," and he expressed concern that even the healthy children of people affected by leprosy face difficulty in getting educated and finding employment. To bring about change, he said, "it may be necessary to frame legislation and adopt policies and strategies that, by providing leprosy-affected persons with their basic needs, will enable them to attain their fundamental right to live with dignity." He also appealed to companies and NGOs to create more job opportunities for affected persons.

Another senior government official, Delhi's Chief Minister Sheila Dikshit, received an ovation from delegates when she announced that she would be raising the monthly allowance for persons affected by leprosy from Rs. 850 to Rs. 1,000. She also said that she would be considering other measures to improve the lives of those living in the capital district.

EMPOWERMENT SESSIONS

The core of the conference was devoted to the voices of people affected by leprosy. The day's two "empowerment sessions" gave colony representatives from around India a platform to talk about the everyday problems and hardships they and their communities face, and suggest solutions.

Girdhari Lal (Delhi), called for children of people affected by leprosy to receive a proper education, which would help them to achieve selfsufficiency. He also sought property rights for affected people and said they should have their own representative in the nation's Parliament.



Vice President Bhairon Singh Shekhawat

Zainuddin (Jharkand) talked about how affected people are pushed away from their land and property and made to live far from cities in leprosy colonies where they cannot find appropriate sources of livelihood. "Where should I go? I am a citizen of this country, a son of this land. Then why is there no place for me?"

C. L. Mishra (Punjab) also brought up the lack of employment opportunities. "People affected by leprosy don't want to be beggars by choice," he said. "They want to work and earn a living. But they do not get any work."

"People affected by leprosy don't want to be beggars by choice"

In one of the most powerful testimonies, Maya, a wife and mother from Delhi, described her experiences married to a person affected by leprosy. The couple have two sons, but it was difficult to find a school that would take them. Finally, after many requests, the boys were accepted, on condition that they sit apart from their classmates. "I just want to say that I and my sons have been living with my leprosy-affected husband for so many years and are perfectly healthy. There is no need to discriminate," she said.

The day following the conference, there was a meeting of the National Forum, which is made up of colony representatives from around India. Members agreed that the Forum will be established as a trust with two chapters — one for the northeast of India, and one for the rest of the country — and confirmed that it would be an organization composed of, and for, people affected by leprosy. Efforts by India's leprosy affected to help themselves are thus gathering pace.