



Health e-Letter

Letter from the Editor

There is something magical about turning nineteen: You believe you were meant to change the world; you believe in life's goodness. And you believe in the power of your dreams.

Now, for a moment, imagine a child who witnessed his mother being brutally abused; his parents dead before he could even start going to school; his home taken away before he knew what a shelter meant and he carried the label of HIV before he could learn ABC.

Would the magic of nineteen work for a child with so fractured a past?

Ask Murugesh. He lost his parents to AIDS at an early age. He was brought up at a care and treatment centre in Bengaluru called Freedom Foundation. He saw his friends die of AIDS. He lived each day as though it were his last. Murugesh recently turned nineteen.

The magic is apparent in his eyes. He is thrilled to be alive. He dreams of becoming a painter. He excels at the computer. And he is training in vocational courses to earn a livelihood.

Murugesh is among the first few positive children to grow into adulthood, which has thrown up several questions and ethical issues before Freedom Foundation. For instance, where does Murugesh go from here? How will he find his confidence in a discriminatory society? How will he handle his sexuality? And many more.

Ashok Rau who set up the first centre of Freedom Foundation on the outskirts of Bengaluru to provide a home for positive children, admits facing an ethical dilemma as these children move into adult life.

Does the home continue to keep the children even when they are young adults or send them off?

Answers to the issues are not easy. They need to come from communities and larger civil society. The fact is Murugesh and young positive adults like him would need lifelong support from families and communities to lead productive lives and look after their health.

This brings us back to a debate we had initiated earlier – whether institutional care should be encouraged? Twenty years of living with HIV has done much to change old mindsets and attitudes. Now we know, with proper counseling and education, it is possible to get children integrated with their extended families even after the death of parents from AIDS.

Our story from Nagpur brings up the issue as a school is started exclusively for HIV positive children. If there is one enduring lesson from Murugesh's life, it is that this is not the way forward.

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Starved of food, people refuse polio drops for children

By Manoj Pratap

Patna: The poor in Bihar's villages are protesting against the state government's indifference to their plight by refusing to participate in the pulse polio programme. In several district across the state people have not allowed polio workers to give the vaccine to their children.

In some villages people have turned away workers saying saving their children from polio alone would not help them, especially when they were not sure about their own survival. People in the villages of Saran, Danapur, Madhubani, Sasaram and Bhagalpur virtually blocked the last pulse polio drive.

"No one from our village will allow pulse polio volunteers to give drops to children," says Radhakishan, a youth from Pathra village of Saran district. He says they did not receive food or any other supplies of essential commodities after the floods, as promised by the Nitish Kumar government.

"Around four to five thousand families of the state have boycotted the pulse polio drive," says a health official. "People are linking the issues of development with the polio campaign. They have decided not to participate in the program until they are provided below poverty line cards, access to Indira Housing scheme, old-age pension schemes and other government facilities," he said.

The state immunization officer, Dr. Gopal Krishna, admitted that people were resorting to this boycott to draw the attention of the state government towards the problems faced by them. "Steps are being taken to solve their problems instantly so they bring children to pulse polio camps. District magistrates, block development officers and sub division officers are addressing their problems," he said.

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Villages in Danapur district, which borders the capital city Patna, have also refused to take polio drops. Their reasons too are similar. They say the government has not brought any of the development programmes to their villages.

In the Saranv gram panchayat of the district polio workers were not allowed to enter the villages. "People said they would keep boycotting the polio campaign until their demands on development were met," medical officer of the block, Dr Bhola Chaudhry said.

In Madhubani and Bhagalpur too people boycotted the polio drive to protest against irregularities in allocation of flood relief material. "With government's callousness, our survival after the devastation from the recent floods has become difficult. What is the point of giving polio drops to our children if we are not sure about our own survival?" questioned a villager.

The residents of Dinara block of Sasaram are also staying away from the campaign and have decided to do so until proper water, power supply and roads are provided. Fifty children from 57 families of the village did not take polio drops during recent drive. Earlier too people from this block had boycotted the campaign after demolition drive was carried out in the area.

DISTRICTWISE NUMBER OF POLIO CASES IN BIHAR

(Till mid-April 2008)

Samastipur	25
Darbhanga	21
Muzaffarpur	13
Khagaria	10
Madhubani	8
Saharsa	8
Purnia	8
Sitamarhi	6
Patna	6
Nalanda	6
Begusarai	5
Madhepura	5
Vaishali	5
Nawada	4
Champaran East	3
Supaul	3
Saran	3
Araria	2
Bhagalpur	2
Munger	2
Sheikhpura	2
Katihar	2
Kishanganj	1
Lakhisarai	1
Champaran West	1
Jamui	1
Aurangaabad	1
Bhojpur	0
Buxar	0
Rohtas	0
Jehanabad	0
Siwan	0
Gopalganj	0
Sheohar	0
Arwal	0
Banka	0
Gaya	0
Kamur	0
Total	154

Mark of stigma: A school for HIV positive children

By Shekhar Deshmukh

Nagpur: Is it in the interest of HIV positive children to start a special school for them? Or would it only serve to fuel more stigma and discrimination?

A debate has started in this city after a proposal for setting up a special school for positive children was cleared recently by the assistant commissioner of Nagpur's Municipal corporation Atul Patne.

Many experts have criticized the move saying HIV positive children need to be nurtured and supported within their communities. Special schools and hospitals would only ostracise them instead of integrating them with larger civil society. Ashok Rau at the Freedom Foundation described this as an "isolationist strategy" which would have extremely adverse impact on the children, the issues and society at large. Anand Grover from the Lawyers' Collective called it "social discrimination." Dr Alka Deshpande at J J Hospital said it would only add to the stigma.

Interestingly, the proposal was moved by the positive peoples' group in Nagpur, Sahara Bahuudeshyeya Sanstha. Patne, who comes from the Indian administrative service (IAS), has taken the responsibility of running the school located in Nagpur (east) Indora no.2. Municipal corporator, Dr Milind Mane, who is also a doctor, has said that he would provide his services free-of-cost.

In fact, the proposal for setting up the school was submitted to the municipal corporation by Dr Mane last year. At a function on World AIDS Day, Patne announced that the proposal had been cleared. The school became functional within a week. Initially 28 students were enrolled in the school but eight dropped out. Mane says they have registered 35 students for the next academic year.

Nagmani Marshettiwar president of Sahara Multipurpose Organisation and founder of the school says, "I am HIV positive. Once when I fell sick I was admitted to a hospital. Doctors discriminated against me and I was forced to sleep on the floor. At the time I could not take care of my children as well. If a special school had been there, my children would have been looked after. We must welcome this move."

WHAT EXPERTS SAY

Dr Alka Deshpande, head ART center, JJ Hospital, Mumbai, says that she cannot accept the concept of separate school for HIV positive children. "These children will get further stigmatised with setting up of such schools. Moreover, setting up a school for only 20 to 30 children is wastage of taxpayers' money," she adds. Perhaps, there may be some short term gains, but it will harm us in longer run, she says.

Senior Supreme Court lawyer and project director Lawyers Collective, Anand Grover, says efforts should be made to mainstream infected and affected people. "To set up a separate school for HIV infected and affected children is completely wrong. It is against humanity and equality." Grover said in the early seventies some schools were setup for medically challenged children in the US, but such efforts never got social support and most importantly never had the desired impact.

Ashok Rau from the Freedom Foundation underscored similar views saying running a separate school is not a long term solution. "While Mr. Atul Patne may have thought of a proactive solution to the issue of stigma and discrimination by setting up a separate school for HIV positive children, this is a knee jerk reaction. This kind of isolationist strategy will have extremely adverse affects on the children, the issue, and society at large. There are good practices around the country that have mainstreamed HIV positive children in regular schools. I can give the example of Freedom Foundation. We have a thousand positive children registered at all our units

across the country. We had to fight tooth and nail with various schools but we now have a few schools that accept our positive children."

Rau said "by setting up parallel initiatives we unwittingly create more isolation, leading to more stigma and discrimination, not to mention the additional trauma of isolation, stigma and discrimination that these children are put through. In many cases this tears families apart as siblings are separated at school and home. We must remember that these are adult choices and not children's."

Echoing similar views, Dr Milind Bhurshundi from Lata Mangeskar hospital in Nagpur said: "At a time when we were trying hard to resolve the problems of stigma, discrimination and confidentiality, setting up of such school will make our task more daunting."

Sanjivini of positive network supported by the Nagpur positive peoples' group, NMP plus, says such schools are welcome provided non-positive children also enroll themselves. "Providing nutrition, treatment and education to positive children is a good step. The media has in fact sensationalized the issue and blown it out of proportion," she added.

President of NMP plus, Shabana Patel, feels that such schools will only fuel discrimination. "When these children grow up, we would have to set up separate colleges and work places for them. What are we trying to convey by setting up such schools? We must try to make our society inclusive," she added.

She said her own children were studying in this school. "Those who are criticizing this move did not come forward to help us when we were suffering. Those who were neglected by society are studying in this school."

Government data shows that there are at least 10,000 HIV positive people in Nagpur. Milind Mane, however, added that the figure might be around 40,000 of which 500 would be children. "Several of these children are orphans. And when they wish to go to school, they are told that you are going to die anyway so why go to school," he added.

Medical treatment, education and nutrition are major issues for positive children, said Patne. He agrees that bringing these children into mainstream society and ensuring proper space for them is the ideal approach. However, he says, "no one takes care of these children once their parents pass away."

"People have a tendency of opposing new things. When noted social activist Dr Baba Amte tried to set a separate place for people suffering from leprosy in Anandwan, he faced stiff opposition. But now see, we buy products made by them and eat their products, in fact I have eaten food prepared by them," he said.

"We talk about getting rid of stigma and discrimination associated with HIV positives, but what are they supposed to do till these problems are resolved," questioned Patne.

Schemes alone do not help women survive child birth

By Sudhir Mishra

Lucknow: Maya Devi, a dalit woman, was escorted to a community health centre in UP for safe delivery by a health worker. However, the staff there refused to take her in. Instead they asked her to go to a district hospital.

ASHA (Accredited Social Health Activist) who had taken Maya Devi for safe delivery under the Janini Suraksha yojana (safe motherhood scheme) of the ambitious National Rural Health Mission (NRHM) had to transfer her to the nearest district hospital where she delivered a boy.

Maya Devi was fortunate to get the required medical attention at another hospital. More recently, a dalit woman died after she was forced to go through a seven-hour-long labour at a cycle stand as a hospital in Kanpur refused to admit her. She delivered a still-born and died soon thereafter.

A spokesperson of Health Watch says on November 30 last year two women, Kamla and Devrani, died during child birth at a hospital in Kanpur. These women had been taken to the hospital by the ASHAs after convincing them that it was safer to go for an institutional delivery. In these two cases the head nurse at the hospital had taken 500 rupees and two other nurses took 50 rupees each as a tip. When these women started bleeding heavily they demanded more money. By then the two could not be saved.

In our last issue we had reported the case of Celenta, who was thrown out of the health centre after a health worker injured her during delivery leading to a vesico-vaginal fistula. For a year Celenta went from one hospital to another trying to find why she had lost control over her urinary bladder.

While the government has launched one of its most ambitious schemes to provide hospital care for women during child birth, not much has changed at the ground level. Poor infrastructure, absence of trained staff and an attitude of indifference towards the plight of the poor and marginalized has led to death of women at the health centres. In a random survey it was found that in 132 government hospitals in the state, only six doctors, six ANMs and five staff nurses were available who were trained to handle child birth.

A survey that was conducted in 10 districts of the state by Health Watch, a non-government organization from January 2007 to February 2008, found 72 cases of such carelessness. Health Watch found that pregnant women were denied medical help if they did not give money

MATERNITY CARE IN UP AT A GLANCE:

48% women do not undergo any kind of testing in government hospitals.

30% do not get any immunisation during pregnancy.

80% do not get iron and folic acid tablets.

70% deliveries take place at home.

IN EVERY 100,000 DELIVERIES, 7,300 NEWBORNS AND 517 WOMEN DIE

to hospital staff. Eight women died during child birth itself.

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This correspondent spoke to several ASHAs who confirmed that it was difficult to get medical care at any of the community health centres. The ASHAs had to first work with the women in the villages and convince them to come to a medical facility instead of depending on the local midwife for delivery. But often they were unable to find medical help in areas closest to them and had to travel long distances to go to a district hospital.

Shakuntala Devi from Healthwatch has demanded an inquiry into recent case of death. "This is not the first time a woman has died due to carelessness. In 2005, a woman gave birth to a dead child in the Mohanlalganj Community Health Center. Here also the staff demanded money from the family."

Processes come in the way of second line drugs for poor

By Shekhar Deshmukh

Mumbai: Hiralal is on first line anti retroviral therapy. Of late, he has been showing worrying signs of progression towards AIDS. One such indicator, the viral load in his blood, has reached 94,000. This can be brought down only by starting him on second line drugs.

These potent drugs are life-saving for patients who develop resistance to the first line of treatment. In January this year the government allowed second line drugs to be given free-of-cost to a few patients after careful screening. The J J Hospital at Mumbai identified Hiralal for receiving second line drugs.

One day Hiralal got a phone call asking him to get some tests done for the second line treatment. Living in Panvel, about 170-odd kms from Mumbai, he borrowed some money and rushed with his wife to JJ hospital.

At J J Hospital, Hiralal was asked to appear before a committee. The committee members asked him several questions. Hiralal was told after a long wait that his CD4 count at 214 was not too low. Therefore, he could not be given second-line drugs. Government guidelines stipulate that second line therapy can be started only if a person's viral load is above 10,000 and CD4 count below 100.

Guddi Singh's story is a little different. With a CD4 count of 100 and a failing immunity, JJ Hospital recommended her for the second line therapy. In her case the committee agreed that second line drugs should be started immediately.

She was asked to get some tests done. Her blood samples were taken. But even after a month the results have not come. The hospital is helpless. Without the results of the tests they cannot start her on second-line drugs.

The scheme to provide free second line anti retroviral therapy announced by health minister Anbumani Ramadoss four months ago is plagued with far too many issues of implementation. Till date around 7500 patients at JJ Hospital have received anti retroviral drugs. Of these only eighteen are on second line drugs. People who need these drugs free of cost are poor and often debilitated by opportunistic infections as a result of their failing immunity. They have

The National AIDS Control Organisation has drawn up an intricate system to assess each case before starting second line therapy. It has set up a five-member committee, State Aids Second Line ART Clinical Expert (SACEP), to review each case that is recommended for therapy. In Mumbai, the Committee reviews these cases every Tuesday after which blood samples from patients are sent to Kasturba Hospital, about 2.5 kms from J.J Hospital. The process, however, is not as smooth. Kasturba Hospital takes about a month time to conduct the tests and give reports. They need at least nine samples for optimum cost recovery. This takes time and patients suffer. JJ Hospital is helpless. They have the necessary equipments for the tests. However, they have to follow the directives of the National AIDS Control Organisation and the Mumbai AIDS Control Society.

to visit JJ Hospital several times, appear before a committee and go through lengthy processes of tests.

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Head of ART center at JJ Hospital Dr Alka Deshpande, says that they are only following the guidelines set up by NACO. "If patients are suffering because of the process, we will take up the issue with the NACO," she said. "The decision to send samples to Kasturba hospital was taken by NACO," she added

Dr Deshpande said the situation could improve after proposals to start second line drugs at three other hospitals are also approved. Talking about lesser number of patients getting second line drug, she said: "Chennai and Mumbai hospitals are able to give these drugs to 30 patients. We hope that with more number of centers more patients would be able to take the drugs."

The scheme to provide free second line drugs was launched with great fanfare. A large sum of money was spent on training Indian doctors and technicians. They were sent to Bangkok for training workshop. But the beneficiaries of this scheme are still running from pillar to post to get the required treatment.

Tobacco chewing makes Bihar lead in mouth cancer cases

By Jitendra Jyoti

Patna: The number of cancer patients in Bihar is increasing steadily. An estimated five to six per cent of the state's population could be suffering from different kinds of cancer, says a study done by the Mahavir Cancer Institute, one of the few specialized cancer care centres for eastern parts of India, located in Patna.

There are an estimated 300,000 cancer patients in the state. Tobacco-chewing habits of people in the state have put mouth cancer as the commonest form of cancer in the state. Cancers of lung, gastro intestinal tract, throat, gall bladder and lymphomas are also common amongst men. Women mostly suffer from uterine, breast, gall bladder and blood cancers.

Oncologists at the Institute say due to lack of awareness people delay their treatment. Often patients with mouth cancers come to the hospital only in the third or fourth stages. Survival then becomes difficult. A senior consultant at the Mahavir Cancer Institute, Dr S H Advani, says the early symptoms of mouth cancer can remain hidden for years. By the time people come to the hospital, it is too late for treatment. Mouth cancer is closely followed by lung cancer in men, which occurs mostly due to smoking.

Children in Bihar, it seems, start smoking at a rather early age. An oncologist at the Institute, Dr VP Singh, says a study on patterns of smoking amongst children which covered 13 states in the country, revealed that 54 per cent of children below 10 get into the habit of smoking. In Bihar, however, they start much younger --- by the age of seven or eight.

A large number of women in Bihar suffer from uterine cancer. Dr Singh says that 40 per cent of women in Bihar suffer from uterine cancer, which is higher than national average of 25-30 per cent.

Interestingly, a far less number suffer from breast cancer, perhaps because most women breast feed their babies. The study shows that only 12-15 per cent women suffer from breast cancer, which is lower than the national average of 18 per cent. In developed countries, 25 per cent women develop breast cancer," says Dr Singh.

In comparison to men, more women in Bihar suffer more from gall bladder cancer. "Eight to 12 per cent of women suffer from this cancer. It has been found to be more common in women who live on the banks of the Ganges river," says Dr Singh.

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Fifteen years later baby food case drags on

By Manoj Ojha

New Delhi: In 1992, a pediatrician, Dr Arun Gupta, decided to take on powerful multinationals such as Nestle for violating Indian Milk Substitute, Feeding Bottles and Infant Foods (IMS) Act. Fifteen years later the case is still dragging on even as Gupta, now the national coordinator for Breastfeeding Promotion Network of India (BPNI) valiantly continues the fight.

The case was filed on behalf of ACASH (Association of Consumers Action on Safety and Health) as the infant food was advertised as suitable for feeding a baby from four months of its age. ACASH also objected to the company's failure to translate information into Hindi.

The case filed in the court of a metropolitan magistrate got its first boost when in February 1995 the court admitted the case and gave permission for future hearings.

Meanwhile, Nestle decided to challenge the basic Indian law to promote breastfeeding and filed a petition in the Delhi High Court in December 1995. In its petition against the Union of India, the company challenged the IMS Act, and asked for a stay on some of its crucial provisions. Nestle said the law was inconsistent with other laws such as Prevention of Food Adulteration Act (PFA) and that IMS could not be followed while the PFA act was in force.

The case in the Delhi high court dragged on. Between August 1997 until September 13, 2000 there were as many as 17 adjournments, says Gupta. Fourteen of the hearings were adjourned because of Nestle, one was sought by ACASH and on two occasions either the judge was on leave or it was a court holiday.

In January 2001, the government's prosecutor opposed the stay sought by the Nestle counsel. The court asked the Nestle counsel why they were seeking adjournments time and again and then the judge fixed April 23, 2001 as

FOR THE RECORD							
Case filed against Nestle for violating infant food Act	Court gives permission for hearings	Nestle challenges IMS Act in Delhi high court	Lower court orders closure of case	Date of final hearing in high court. Matter still pending	Case reopened in lower court	Arguments begin	Judge changes
1992	1995		1997	2001	2002	2007	April 26, 2008

final date of hearing into the matter. The matter is still pending with the High Court.

In the court of the metropolitan magistrate as well Gupta started to come up against hurdles. In November 1997 the court ordered the case to be closed. "I realised I had made mistakes with legal technicalities of the case and the case was closed inadvertently. We fought tooth and nail and succeeded in getting the case opened after a gap of around five years. On February 13, 2002 the court ordered that the case must move and recorded in the interest of justice," says Gupta.

Nestle challenged the lower court's order in the sessions court but was unable to get any reprieve. However, when the case did come up for hearing, it was found that the crucial piece of evidence - two tins of baby food - was missing from the court's almirah!

Once again, it required some effort to move the case in the absence of crucial evidence.

Arguments of charge against Nestle finally began in October 2007. As the evidence in form of tins of baby food 'went missing', several clippings of the company's baby products were produced in the court, which the defendant out rightly rejected terming it to be their opponents plot to malign the company's image.

After two hours of lengthy arguments, the court fixed November 3, 2007 as the date for next hearing. However, as the judge was on leave on that date so the next hearing was postponed to December 1, 2007. The next hearing was for April 26, 2008.

On April 26 the judge got changed. The next date of hearing is in June.