

| SPECIAL FEATURE |

LIVING WITH HIV

After page 3

Little Akib was in the last stages of advanced AIDS. A boy of 12, he looked six years old and was all skin and bones. He breathed his last on Sunday night. "He was fine this morning, talking and getting ready. I fed him as usual," said his *nani*. She has now watched both her daughter and her grandson die of the deadly disease that is AIDS.

Akib was diagnosed almost three years ago. He wouldn't let it get him down though. Akib would come himself, every month or so, all the way from Gazipur where he lived with his grandmother, to collect his medicine from the hospital in Dhaka. "Whereas I should be the one bringing him for treatment, he would bring me, because he knows his way around the city and knows his letters," said his grandmother. Akib lay beside her, unable to talk or move. His mother had died of AIDS two years ago and his father too had advanced AIDS.

Two months ago, he caught tuberculosis (TB) as well and this, in addition to the HIV virus, combined to weaken him substantially. For those with HIV, the immune system is suppressed, making it harder to fight off other infections. TB is responsible for the most deaths among people with HIV.

His counsellor at Ashar Alo Society (a local NGO), Azhar Hossain, says that Akib should have been hospitalised after he caught TB. A wilful child, however, Akib refused to stay in the hospital and would always go back to his grandmother. "We couldn't enforce that he took the TB or the antiretroviral (ARV) medication regularly at home. Try as we would, he just wouldn't stay at the hospital," said Hossain.

Of the 11,700 adults and children presently living with HIV in Bangladesh (as of 2016), only 2,475 are on ARV therapy. Many remain unaware of their HIV-positive status. Within the last year, almost 1,000 died as a result of AIDS and new infections amounted to 1,500. The figures for this year will be released by the government today.



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PHOTOS: KAZI TAHSIN AGAZ APURBO



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December 1—World AIDS Day.

Stigma runs deep

There remains a silence around the virus and disease and stigma runs deep, even among the HIV-positive themselves as well as in the medical community.

Internalised stigma among those living with HIV/AIDS is not uncommon. A study by UNAIDS, Plan International, BRAC and others found that 68 percent of people living with HIV/AIDS (PLHA) felt ashamed and 54 percent felt guilty due to their HIV-positive status. Shame and guilt hinder their participation in social activities and lead to withdrawal from their communities.

More worryingly, it can prevent them from going to the hospital for treatment. The same study found that 17.1 percent of males and 16.3 percent of females surveyed would not visit the hospital even when they needed to—to collect their medicines or to avail treatment—as a result of internalised stigma.

Equally worrying is stigma from healthcare

workers. PLHA are further discouraged from seeking treatment because of discrimination they face at hospitals and clinics. In a 2010 study which surveyed doctors, nurses, medical technicians and support staff, the results proved troubling. 47.9 percent of healthcare workers felt that those who have HIV/AIDS should not be allowed to mix freely with other people. A breakdown reveals that 21.9 percent of doctors, 48.1 percent of nurses and an overwhelming 83.3 percent of support staff felt this way. With direct caregivers displaying such attitudes, it is of little surprise that patients are discouraged from seeking out treatment.

Testing and treatment are free. As are ARV drugs, which are distributed by the government and, until recently, by a few non-government organisations. PLHAs, especially those diagnosed late, require these medicines every day, for the rest of their lives. They can lead healthy lives as long as they take ARV drugs to control the infection and prevent transmitting the virus to others.

The recent change in the distribution of the free ARV medication is a complication. Earlier, patients

would get their drugs from NGOs and self-help groups, such as Ashar Alo Society, Mukto Akash Bangladesh, and Confidential Approach to AIDS Prevention (CAAP). These organisations have been working to provide counselling, psychosocial and medical support to PLHA across the country. Most of the staff themselves are people living with HIV.

Since October this year, these drugs are now being distributed from six major hospitals around the country, including Bangabandhu Sheikh Mujib Medical University (BSMMU) and the Infectious Diseases Hospital (IDH) in Dhaka. It however means that patients come from as far away as Comilla to get their supply of medicines once every two months.

Sherin Akter says her husband, a businessman, is threatening to stop going to the hospital to pick up his HIV medication as the process is time-consuming and a hassle. Sherin and her husband are both HIV-positive and were diagnosed 11 years ago.

The trouble is not just the usual troubles associated with accessing services at government hospitals. It is that the hospital environment itself is not hospitable for those with HIV/AIDS. Sherin, for example, went for a routine eye exam at BSMMU just last week but was forced to disclose her HIV-positive status to the doctor and nurse, crammed in with five other patients in the doctor's room.

Whether or not to disclose her HIV-positive status in light of the discriminatory attitudes towards PLHA is not a light dilemma. Sherin disclosed it, thinking that her doctor ought to know before examining her. "It was so embarrassing, the doctor and nurse just stared for a long time, dumbstruck as to what to do. Everyone else was also staring at me," she said.

34-year-old Sherin has not yet informed her own family, except her younger sister, of her and her husband's HIV status. Her in-laws found out a few years ago when her husband was severely sick and had to be hospitalised. "It took them a while, but they soon came to terms with the situation," she says. Their only daughter, 14, doesn't yet know. Sherin and her husband have discussed it, but feel that she should be a little older when she finds out that both her parents are HIV-positive. "We plan on telling her once she completes her HSC exams," says Sherin.

Sherin and her husband have faced discriminatory attitudes at hospitals. They have been denied or reluctantly given treatment at least four times because hospitals and doctors are not prepared to treat HIV-positive patients. Remaining silent about their status in public life is a given here, but should they also have to suffer stigma in a place

where they are supposed to receive care?

Holistic care needed

As important as the medicine, is the counselling and psycho-social support required by PLHIV. Dr Saima Khan, UNAIDS country manager for Bangladesh, says "Four things are of essence—confidentiality, access to medicine and services, acceptance of their situation, and help in coping with their families."

Though one of these functions has now shifted to the government, the others remain lacking. Even in the case of medication, they may very well be free but there are hidden costs involved. There are only six hospitals across the country giving out free medicines, testing and treatment. Patients come from afar and are sometimes forced to turn back that day with no medicine or treatment as doctors are not available at all times and there is no privacy for PLHA.

Given these challenges, the transition to a public distribution system should have been better thought out, feels Hafizuddin Munna, president of the PLHIV (persons living with HIV) network. The logic was that the public system is already equipped to handle hundreds of thousands of patients. Why shouldn't it be able to provide treatment to a few thousand?

Hafizuddin worries that the government will not be able to provide comprehensive care in relation to the unique challenges PLHA face. "Service providers are generally not trained to be sensitive. And people in our country are already reluctant to access government healthcare," he says. The service used to be available locally, with NGOs often paying home visits. Now, patients have to make trips to the hospital. "The service needs to be incentivised," says Hafizuddin.

Dr Belal Hossain, deputy director and programme manager of the national AIDS/STS programme says however, "There has been no problem so far in unique delivery. The system is very much the same as before, with PLHA being given two months' worth of medicine and confidentiality being maintained." Dr Belal says that the shift from the NGOs to government had been anticipated earlier and the transition happened smoothly.

But as Akib's case illustrates, just providing medicines is not enough. For Akib, who lost his mother, more care was needed than just telling him to come pick up his medicines. He needed care that went beyond. If he had had that, maybe he wouldn't have left this world at the tender age of 12.

| CORRUPTION |

For a few years now, the National Curriculum and Textbook Board (NCTB), the largest state-owned publishing house in the world, has been immensely criticised by civil society for their misprints, factual errors and ideologically inappropriate content. What was missing from the conversation was the breadth of the problem—and that is what came out when Transparency International Bangladesh (TIB) published their research paper on November 13.

The study took almost a year to complete and reveals some horrifying aspects of NCTB's activities. Misspelled words, incorrect grammar, inappropriate teachings—what might seem like minor mistakes from the surface hides a system of irregularities and corruption. The report concluded that the independent government body is a mess. For example, according to the study, which interviewed numerous officials within the NCTB and outside, only the ruling party loyalists get picked as members of different committees. In some cases, members get excluded even if they are actually competent. According to one informant, who was an excluded candidate, "I have never been called by the NCTB, because the only qualification required for the selection of committee members is political influence." This is in spite of the fact that NCTB is ideologically supposed to be an independent organisation.

The same thing happens when it comes to selecting people for the writers' panel, as many of the writers are picked through favouritism, personal choice and recommendations from the ministry. Many of them lack proper understanding of the curriculum, according to the report.

When contacted, the NCTB Chairman Narayan Chandra Saha informs us that they are also looking into the matter and since the different ministries are involved in the whole process, he cannot give any statement alone, without their opinion. Professor Dr Mohammad Nizamul Karim, Secretary, NCTB, also refused to say anything.

A serious outcome of favouring political partisanship is that people with actual qualifications are left out. Although there is a policy for employing at least one expert from each subject for editing the textbooks of each grade, there are instances where the editors brought in have no significant expertise.

The report stated that this was also observed in the primary education wing. Instead of hiring experienced experts to strengthen our primary education curriculum, they take in regular employees from the education ministry, who often do not have subject-specific expertise. Many are simply cadres who chose "education" as their sector when passing the Bangladesh Civil Service (BCS) exam. It does not mean their university training is in designing textbooks.

Rasheda K Choudhury, Executive Director of Campaign for Popular Education (CAMPE), sheds light on the importance of having experienced people in creating the curriculum. "According to pedagogy, we call it 'developmentally appropriate curriculum and textbook', where a

textbook is prepared considering the age, intellectual capacity and psychology of the students. This process requires an expert who understands these aspects well. Simply employing government employees who were placed in the education cadre in their BCS exam will not work if they don't have the required experience or expertise," she adds.

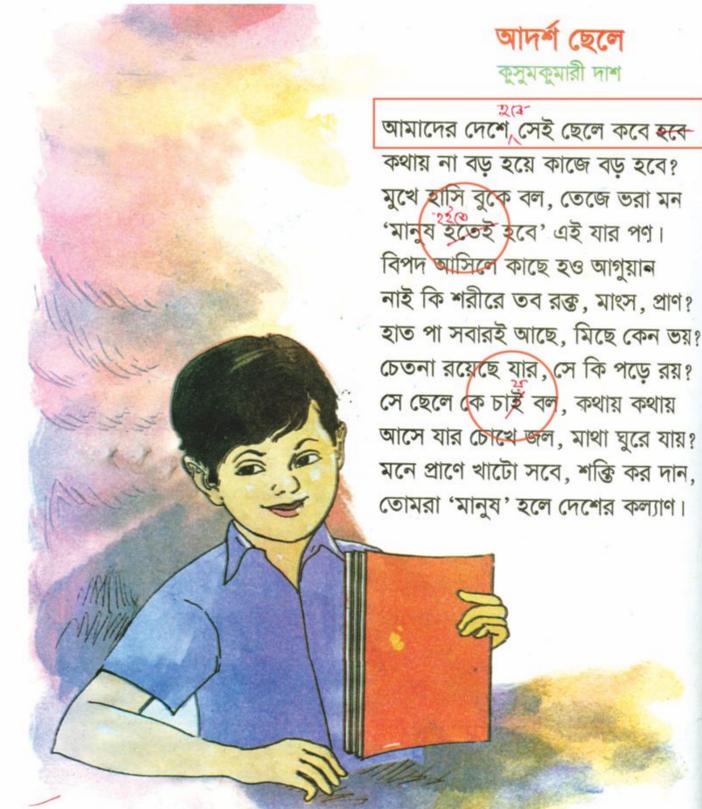
Renowned academician Hossain

presses for a whole month, resulting in delivery delays of the ninth and tenth grades. This happened in 2012.

The report also unearthed that in the beginning of 2016, a number of madrasa leaders met with NCTB demanding the curriculum be changed according to their interests. The NCTB gave in to the demands. For example, a textbook for the madrasa system had a character

BEHIND THE SCENES OF NCTB'S BLUNDERS

NILIMA JAHAN



Zillur Rahman, who was a former advisor to the caretaker government, also agrees with Chowdhury that since NCTB's activities affect the development of children, the organisation should be more careful and conscious while appointing an expert. "If you compromise with merit, you cannot compensate for the impact! It will influence the entire system," he says.

This is something that actually happened because of taking in political favourites. *Dainik Shikkha* published an article in May 2017 recounting how an education ministry official eliminated Abdul Hakim's poem "Bangabani" and Abu Jafar Obayedullah's "Mago, Ora Bole" and put in his own creations instead. To do this, he stopped the

called Uttam. The madrasa leaders changed it to Oliul because Uttam sounded like a Hindu name.

Another thing the report revealed—the local and revenue audit team took BDT 8-10 lakhs every year for the past few years so that such irregularities are not shown in their audit report. In the 2016 academic year, with the initiative of audit and budget officers, a total of BDT 1,624, 000 was collected from the monthly salaries of different employees to pay BDT 20 lakhs to the audit team. The rest of the amount was taken from the budget.

This is one example of the irregularities of the body—over BDT 50.96 lakh was spent in the last three academic years for minor tasks like

making guidelines for tender, publishing advertisements, issuing work orders and preparing a list of books sent to the upazilas. However, when asked, Mohammad Monirul Islam, the Chief Accounts Officer of NCTB, informs us that he knew nothing about it.

Malpractice has also been found in the printing phase. In the 2015 production year, the estimated production cost of each forma (double dimai paper) was BDT 0.85, which increased by 60 percent in the following year. There are allegations that the contracting process was biased—that both the tender committee and printing association members were informed about the projected estimated cost before inviting tenders.

According to an owner of a printing press interviewed by the researchers, it is strictly mentioned on the tender notice that each printing press must have 23 by 36 inches size printing machines, sheet machines and UV for binding covers, as well as necessary equipment for lamination, along with their own printing and binding factory. But, most of the small printing presses do not have their own binding arrangements, and hence, they outsource. "The thing is, there is a clear difference between the quality of work of a contractor and sub-contractor—a contractor might work for the goodwill of his company, but a sub-contractor usually does not care about it," he says.

Besides, people who are supposed to monitor the quality are allegedly negligent in their duties, and the presses can get away with using lower-quality paper. According to the informer, the presses use good quality paper during daytime, but switch out at night. These books are then sent to the schools of different upazilas.

The upazilas also bear the brunt of irregularities in the case of distribution. According to a 2017 NCTB report, around 50 percent of the books were not distributed in time to nine upazilas of Laxmipur, Noakhali and Chittagong. But, the inspection report shows that all books were distributed on time.

However, Md Farhadul Islam, the new Chief Distribution Controller of NCTB, informs us that he does not believe that this is entirely true. "Last year a shipment arrived in time, but we were not able to receive it within the deadline because of formalities. That is why we tried to bring books from other districts and arranged book festivals in different upazilas of Laxmipur and Noakhali districts," he says. Islam also assures us that since the information regarding malpractice and irregularities have come out, they are careful about the matter. "I believe that whoever is responsible for this, whether it is NCTB or printing organisations should come to light," he adds.

Though a large number of media reports have been published in recent years on NCTB's massive blunders, compared to that, no significant steps have been taken by the respective authorities to look at what is actually going on there. However, time has come to give attention to this, as children all over the country should not be deprived of their basic right to education because of malpractice and mismanagement by the NCTB. ■