profession is accountable to and controlled by the new market forces, on whom it is now dependent.

This, in my view, creates an opportunity for the ethics movement in India to engage with the profession on a few new platforms. One is the reassertion of the historically independent ethos of the medical profession, which feels intimidated by the juggernaut of market medicine, with the hope of forging more sustained ties with some of them. The other of participating in the process of restoring its credibility in the public eye by working on a joint programme which respects the rights of patients as well as of health professionals. The time may be ripe for opening a dialogue with professional bodies on these premises, and a beginning has been made by our friends in

the People's Health Movement in Maharashtra with the Indian Medical Association.

I would like to end my presentation on a personal note by sharing a dilemma. I have often wondered whether individuals like me are, by being in the belly of the beast, contributing to the growth of the beast in its present form. Perhaps some of you in the audience may be able to identify with this sentiment when I say that this results in an almost schizophrenic existence. But then as I said earlier in the context of the Medical Council of India scam, the need for alternative viewpoints within the profession today is greater than ever before.

Based on the inaugural plenary address at the Third National Bioethics Conference, New Delhi, November 17, 2010

## Ethics, equity and genocide

## **BINAYAK SEN**

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With its declaration that social injustice is killing people on a grand scale, the World Health Organization, through its report of the Commission on Social Determinants of Health, has brought the issue of equity and health right to the centre of the stage. How do its prescriptions fare when examined against the backdrop of the Indian situation?

India is one of the most inequitable societies on earth, and certainly when its size is taken into consideration, we are responsible for a sizeable proportion of the sum total of human misery on this planet. As health professionals, we have access to data that goes beyond the Dandekars and Tendulkars and Arjun Senguptas, and which we can read off the bodies of our study subjects. We have become inured to the knowledge that, in India, 47% of our children under the age of five are malnourished by weight-for-age criteria. In the last six years, more children have died, across the world, of malnutritionrelated causes than the total number of adults who died in the six years of the Second World War. But let that pass. The next datum that I will place before you is this: 26% of our newborn babies are low birth weight for gestational age. Please remember that this 26% is not randomly distributed across the population, but occurs far more commonly in specific communities, obeying the pressures of inequity and social injustice. And then project Barker's hypothesis - no longer just a hypothesis, alas - onto their future trajectories. See if it helps you sleep at night.

Coming now to the adults, childhood malnutrition is a complex pathophysiological entity, in which the lack of food is only one among a complex of factors. Adult malnutrition is simpler - it means you didn't get enough to eat. The National Nutrition

Monitoring Bureau tells us that 37% of adult males and 39% of adult females in India have a body mass index of less than 18.5, signifying chronic undernutrition. If we disaggregate these figures, we find that this includes 50% of scheduled tribes, and over 60% of scheduled castes. More than 40% of the adult population of Orissa is also below 18.5. The population of Maharashtra, which is considered to be a relatively "developed" state with a high per capita gross national product, has 33% below 18.5. Now the WHO categorises these proportions and says that any community with more than 40% of its population below 18.5 should be regarded as a community in a critical state - amounting to famine.

So now we have a population of which significant and identifiable subsets live in a state of chronic famine from year to year - what I call walking through time with famine by your side. As if this weren't enough, Utsa Patnaik, one of our senior economists, says that from 1993 to 2004, the per capita yearly grain consumption has declined from 178 kg to 156 kg-- that is by 22 kg. Since this is a mean figure, and richer people have actually increased their consumption, the decline at the lower end of the scale is even greater.

So, now we have an ongoing famine, and it's getting worse over time. But, as my friend the Bengali poet Gazi M Ansar puts it, "Here, twilight descends over a vast hinterland, like a tiger's paw: the mullahs' houses are stuffed with grain. The famine is only in our neighbourhood." It is precisely this "neighbourhood," these sections of the population, that are being targeted by the State, which stands guarantor under the doctrine of eminent domain, in a countrywide process of expropriation of natural resources and primary accumulation, including, in the words of eminent

historian David Harvey, "commodification and privatisation of land and the forceful expulsion of peasant populations; the conversion of various forms of property rights (common, collective, state, etc) into exclusive private property rights; the suppression of rights to the commons; the commodification of labour power; and the suppression of alternative (indigenous) forms of production and consumption; appropriation of assets including natural resources, etc. etc." Under this state-based regime, the Gini coefficient, which is a measure of inequality in the economy, has shown a 10% increase, and this is an underestimate, between 1993-94 and 2004-5, the same period as Utsa Patnaik's declining grain consumption.

Now the Indian Constitution is very categorical on the issue of equity. The Directive Principles of State Policy enjoined, 60 years ago, that all state activity must be directed to the removal of inequity and the promotion of equity. And yet, the Indian state has deployed not only the whole of its civil authority but its entire paramilitary forces and up to half of its army in the maintenance of an inequitable regime in which large sections of its population are in a permanent state of famine. The communities thus affected have hitherto managed to survive because of the access to common property resources - land, water, forest - a very special social and ecological niche. By being subjected to displacement on the present vast scale, they will lose their tenuous hold on existence. The UN Convention on the Prevention of the Crime of Genocide tells us clearly that, in addition to direct killing, "the creation of physically and mentally hazardous conditions which could put the survival of particular communities at risk" would also come within the ambit of genocide. But, talking of genocide, Chomsky, in a recent essay, quotes the ancient Greek historian, Thucydides: "Right, as the world goes, is only in question between equals in power; while the strong do what they can and the weak suffer what they must." This is the fundamental principle of international order and, dare one say it, of national order as well.

This being so, and the Indian state having successfully resisted the injunctions for equity embedded in its own Constitution for 60 years, one is led to wonder how it will respond to the sage advice contained in the report of the Commission: close the gap in a generation, improve daily living conditions, tackle the inequitable distribution of power, money, and resources, and measure and understand the problem and assess the impact of action. I am neither the first nor the only one to have had such doubts. Here is Dr D Banerji writing in 2006, in the *International Journal of Health Sciences*, about the Commission while it was still in progress:

The Commission on Social Determinants of Health (CSDH) is the latest effort of the World Health Organisation to improve health and narrow health inequalities through action on social determinants. The CSDH does not note that much work has already been done in this direction, does not make a sufficient attempt to analyse why earlier efforts failed to yield the desired results, and does not seem to have devised approaches to ensure that it will be more successful this time. The CSDH intends to complement the

work of the earlier WHO Commission on Macroeconomics and Health, which has not had the desired impact, and it is unclear how the CSDH can complement work that suffers from such serious infirmities.

It seems that the WHO is accountable for such programs and their massive failures mostly to its dominant fund providers, not to the masses of the poor people of the world. This lack of accountability to the wider population poses a most serious problem concerning the nature of the democratic functioning of the WHO. This needs urgent action. The WHO has to be brought back to performing in accordance with the directives laid down in its constitution and working in consonance with its famous definition of health, which has lately been reiterated by a former director general, Halfdan Mahler. This has to be a political struggle for the neglected peoples of the world to wrest their rights from the hands of those who are using the organisation for their narrow class interests.

I would like to take up the remaining time available to me with two examples of the way in which our system has dealt with putative action on the social determinants of health and then go on to consider how to decide, in our dealings with the recommendations of the Commission, what constitutes the baby and what the bathwater.

So how does the state deal with what we would like to call action on the social determinants of health?

As a longstanding member of the largest human rights organisation in India, the People's Union for Civil Liberties, or PUCL, I am extremely proud of the PUCL's involvement in the right to food campaign which is a campaign towards securing the right to a minimum amount of sudsidised food grains for all the citizens of India. This campaign originated out of a public interest litigation (PIL) brought in the Supreme Court of India by the PUCL more than 10 years ago. While this case still continues, the interlocutory orders passed by the court from time to time constitute the substantial architecture of the public distribution system as it stands today. Needless to say, the right to food campaign is acutely conscious that further improvements are needed in the public distribution system, and, in August this year, at the Right to Food Convention held in Rourkela, the campaign decided upon a set of demands, including universalisation of the public distribution system (instead of the targeted system that obtains at present) and a substantial increase and diversification of the statutory rations allotted to each beneficiary under this programme. These recommendations were raised recently in the National Advisory Council under Smt Sonia Gandhi as chairperson, by, among others, Jean Dreze, the eminent economist, and Harsh Mander, appointed a Commissioner to the Supreme Court under the programme.

To our great disappointment, the National Advisory Council, in a recent decision, has rejected the demands of the right to food campaign on the grounds of resources being unavailable. The campaign has now embarked on a long term public agitation in support of these demands. It is my earnest request to the

General Body of this Conference to pass a resolution in support of the demands of the right to food campaign.

The second example that I wish to bring before you is from the field of tuberculosis - or, rather, the intersection of tuberculosis and malnutrition.

In a country where 33% of the adult population has a BMI below 18.5, and which also has one-sixth of the world's population and one-third of the total global burden of tuberculosis, one would think that the bi-directional association between malnutrition and tuberculosis would be the focus of intense study. This is not the case. India is the single largest contributor to the global burden of morbidity, mortality and drug resistance in tuberculosis. An estimated 8.5 million Indians suffer from tuberculosis. There is an annual incidence of 87,000 cases of multidrug resistant tuberculosis, and an estimated annual mortality of 370,000 persons.

And yet, a recent WHO-based systematic review study which established a consistent log-linear relationship between tuberculosis incidence and BMI was unable to include a single Indian study. Similarly, a Cochrane systematic review of randomised control trials of nutritional supplements for people being treated for active tuberculosis did not include a single Indian study in its ambit. But I would like to draw your attention to two studies that do not figure in either review — the first with pride, and the second with shame.

The first study has been done by my colleagues at the Jan Swasthya Sahyog (People's Health Support Group), a nonprofit voluntary organisation, which runs a community health programme in 53 forest related villages in central India. They have reported an as yet unpublished study on the nutritional status of 975 patients with pulmonary tuberculosis - the largest such study to emerge from India. They report that patients with active pulmonary tuberculosis in rural central India were found to have macronutrient malnutrition, ie. starvation, almost as a universal association, with less that 5% having weights in the normal range. Certain groups like scheduled tribes and women fared worst, with life-threatening levels of under-nutrition. There was evidence of long-standing under- nutrition with low height for age (stunting) in the majority of patients. The report goes on to conclude: "This report is a stark illustration of the adverse synergy of the epidemics of under nutrition and tuberculosis. The consequences are extensive disease on the one hand and severe wasting on the other, both of which can cause mortality independently and in concert. The need to address the nutritional needs of poor patients with tuberculosis is an urgent imperative on scientific, ethical and humanitarian grounds."

However, the fundamental architecture of the National Tuberculosis programme, formulated in 1962, was based on a specific repudiation of this "urgent imperative." This fundamental architecture has been preserved in the present programme; hence this is a current problem. What was the evidence on which this repudiation was premissed?

This brings us to the second study that I had mentioned, published in the *Bulletin of the World Health Organisation* in

1961. The recent Cochrane review of the effect of nutritional supplements in people being treated for active tuberculosis excluded this paper from their review as "the groups were not randomized to different dietary interventions." This study was carried out at the Madras Chemotherapy Centre in Guindy. I would like to read out to you the summary of findings of this study.

A study was undertaken on the diet of 157 patients with pulmonary tuberculosis admitted to a controlled comparison of treatment with isoniazid plus PAS for a year at home with the same treatment in the sanatorium. The patients were drawn from a poverty-stricken section of the community living in overcrowded conditions in Madras City. A comparison has been made of the dietary status of the home and the sanatorium patients before and during treatment, and the role of the diet in the attainment of bacteriological quiescence of the tuberculous disease has been evaluated. Before treatment the patients in both series had poor and similar diets.

During the early months of treatment, the dietary intake of the patients in both series increased. However, the sanatorium patients received a clearly superior diet through the year in terms of total calories, fats, total and animal proteins, phosphorus and several of the vitamins.

The home patients were physically more active during treatment than the sanatorium patients, further the accentuating the dietary disadvantage of the home series. The home patients gained on the average 10.8 lb in weight over the 12-month period, as compared with 19.8 lb for the sanatorium patients. This greater weight gain among the sanatorium patients was not, however, indicative of superior clinical results. The response to treatment (as measured by the radiographic and bacteriological progress) was not directly associated with the level of dietary intake of any of the food factors, either in the patients treated at home or in those treated in the sanatorium.

It may be concluded that none of the dietary factors studied appears to have influenced the attainment of quiescent disease among tuberculous patients treated with an effective combination of antimicrobial drugs for a period of one year. The successful initial treatment of patients at home is therefore possible even if the levels of dietary intake are low.

The fact that such a poor study could play such a critical role in determining the architecture of a programme of such enormous importance shows how politics takes precedence over evidence in such matters.

So I hope I have managed to convince you that any notion we may have, of an easy transition from the popular articulation of demands based on equity and justice to their incorporation into governance, can only be a pipedream, a false hope. The parameters of governance are set by considerations far more inflexible and hard-hearted than notions such as equity and justice.

So do we conclude that the report of the Commission on the Social Determinants of Health is useless? Do we throw out the whole bucketful--baby, bathwater and all?

I would venture to suggest that the answer to this question can only be sought in the common ancestry that many of us share in the realm of the peoples' struggle, of popular movements. I was grateful, on the first day of the conference, to see the typology of struggle that David Legge had talked about. Any changes in governance that we are able to bring about can only be a bonus -- a side effect. Our real efforts have to be concentrated on the terrain of popular consciousness regarding the real determinants of health and healthcare. If we are able to make this change of focus, then we will see that conditions for change are more promising today.

Despite its recent dominance, neoliberalism, based on the theory that economic growth solves all problems, has lost its credibility. The hegemonic status of neoliberalism, the ideology

and practice of the dominance of markets over society has been seriously undermined.

Class mobilisation and politics are critical for health and tackling health inequalities because progressive social and class movements and parties are the dynamic forces pushing for improvements in the human condition.

This paper is based on Dr Binayak Sen's keynote address at the Third National Bioethics Conference on November 19, 2010. On December 24, 2010, Dr Sen was held guilty of sedition and sentenced to life imprisonment. Dr Sen has worked for over 25 years with the most marginalised people in India, devoting his life to the welfare of the least fortunate. We join the many organisations and thousands of individuals in questioning the judgment, and call for his immediate release.

## Conference report

## **MALA RAMANATHAN**

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The theme of the Third National Bioethics Conference was governance of healthcare, addressing issues of ethics, equity and justice. The conference that took place in New Delhi, the fulcrum of policy making in India, attracted over 350 participants from 7 countries. In all there were 58 papers in 25 parallel sessions, and 12 workshop sessions spread over four days from November 17 to 20, 2010.

The inaugural function began with a short film on NBC 1 and 2, followed by the welcome address. Dr George Thomas, Editor, *IJME*, described the work leading up to the conference and called for the collaboration of individuals, groups and alliances for the ethical care of human beings in a multi-disciplinary effort towards constructive debates. Justice Leila Seth (retired) inaugurated the conference and Dr KB Saxena, former Health Secretary, released the conference programme.

In his keynote address, "Ethics, equity and justice: a view from the belly of the beast", Dr Sanjay Nagral, one of the founding members of the Forum for Medical Ethics Society, described trends in healthcare and medical practice in India to locate the debate on ethics and regulation and to identify the response. As a part of the "beast of modern medicine" with an insider's view, he asked himself four questions: How has modern medicine changed in India? How has the medical system viewed these changes? What is the role of governance in it? And what can the movement for ethics do to sensitise people about equity, justice and ethics? The rise in private healthcare and education, the withdrawal of the state from healthcare,

the view of the entire healthcare sector from education to practice to insurance, as an "entrepreneurial opportunity", is giving rise to new conflicts, and unethical practice is rooted in this context. Professional self-regulation has failed. The state has failed to regulate medical practice though we have seen that a determined government can implement the Prenatal Diagnostic Techniques Act if it wishes. He identified the "biggest failure" as the failure to sustain the ethical debate among the healthcare community. Corrupt medical professionals can survive only because their colleagues allow them to do so. He pointed out that all of us are part of this - we need to constantly flag this menace of market medicine, and we need to work with the state on governance, and create a critical base of medical professionals. So, there is a need to bring back public medicine and participate in the process of restoration of public credibility- that will maintain patients' rights and physicians' rights.

Dr David Legge of the People's Health Movement spoke on the "microethics of activist practice" the small choices that we make in everyday life. He described the larger context of healthcare activism: a global health crisis due to social inequities that are reflected in greater morbidity and mortality among the poor. The People's Health Movement, consisting of an international coalition of organisations and networks, has pointed to the social determinants of health, and the political economy of health. It views health as a human right, and has fought for equity sustainability. It views change as being driven