

# **DEFENDING THE HEALTH OF THE MARGINALISED**



**A CHC silver jubilee publication**

**1984-2009**

**Community Health Cell**

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## Foreword

### From Community Health Cell to People's Health Movement 1984-2009 Defending the Health of the Marginalised Communities.

In a society that is highly polarized – socially, politically, economically and culturally -, the right to life of Dalits, Adivasis, other indigenous communities, women, sexual minorities, people living with disability and HIV/AIDS, people with mental health problems etc stands violated in various forms. Right to health and healthcare which is integral to right to life has seen increasing and steady violations in multiple forms all along the history, more so in the current neo-liberal & free-market economy era. It is becoming a great challenge to assert the rights of the communities, to safeguard the various socio-economic determinants of health, to affirm their strengths and the inherent vibrancy in the context of corporate attack on the natural resources, hegemony of dominant classes & castes over knowledge systems and the economic exploitation along with the expulsion of the urban poor from the urban areas, the increasing helplessness Dalits and the people who are mentally ill face in an over-privatised healthcare system which is unaffordable. The weak or malfunctioning public health system has increased the plight of people's helplessness. To assert the identity of the vulnerable communities and their well-being now needs to be seen by all as part and parcel of the right to health.

Asserting the plurality of communities and the well-being of the vulnerable and the marginalised has been the focus and concern of Community Health Cell (CHC) over the past 25 years. **From** 1984 since its inception, when public health was still a neglected field in India and Community Health was just an emerging area of intervention, **to** becoming an active participant in the People's Health Movement (PHM), Community Health Cell has traversed a long path in the last 25 years. During these years it has promoted community health awareness, supported community health action, undertaken research, and evolved educational strategies in community health apart from engaging in dialogue with health policy planners. Though remaining a "small cell" CHC has tried to influence communities, voluntary /non governmental organisations, social movements, and the Government policies by trying to build networks of solidarity and by being a catalyst of change.

In the last 25 years, CHC's efforts in its work with the marginalized communities was to link them to the larger community health /public health movement in the country and to the People's Health Movement (PHM). This ethos evolved from being a small study-reflection-action team from 1984-89 which later on became the **Society for Community Health Awareness Research and Action (SOCHARA)** in 1990 thus representing a collectivity of this philosophy.

From 1984-1993 was a phase of through an intense interaction with health and non-health groups and networks working with or on issues concerning the disadvantaged communities. In the phase between 1994 -1997, CHC expanded community health training at grassroots level, by reaching out to health and non-health groups through multi-lingual trainings in the southern states of India. From 1998-2006 was the phase where contributions to policy advocacy through critical engagement with the State and intensifying the mobilisation of communities to counter the onslaught of globalisation through various initiatives of PHM, was the key focus. Throughout

these years, CHC played its role as a “catalyst” and “leaven” in mobilising communities, and strengthening the health movement at all levels – local, national and global.

From 2006 onwards, CHC has grown both as a “Centre” for health advocacy, promoting public health policy and education in the alternative paradigm as well as an active health advocacy and networking “organisation” building people’s solidarity, and working towards establishing health as a fundamental human right.

Towards focusing on the right to health of the marginalized and vulnerable communities CHC has taken the path of advocacy, networking with different organisations, research, capacity building and direct interventions. **“Defending the Health of the Marginalised Communities”** “which is a compilation of booklets on the status and challenges of the well-being of Dalits, Urban Poor, Mentally Challenged on whom the impact of communicable and non-communicable diseases is more intense than others, is a response to mainstream the issues faced by these communities. While the selected communities are only a representation of the larger marginalized communities, it affirms positively the right to health of all the vulnerable and the poor.

This Silver Jubilee Publication of CHC is a tribute to the oppressed communities of our society who, however, have been in the forefront of all movements in claiming rightful spaces and establishing rights for all and in bringing about a larger social change.

E. Premdas  
Coordinator, CHC/Secretary, SOCHARA, December 2008  
Bangalore.

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## CHAPTER I - HEALTH FOR DALIT COMMUNITIES

### I. WHO ARE DALITS?

Etymologically the word 'Dalit' stands for the broken, the oppressed, the crushed, the ground down, the helpless, the poor and low. It was a term employed by rights activists to refer to 'untouchables'. Mahatma Jotirao Phule and Dr. B. R. Ambedkar used this word to describe the 'atishudras' in the traditional Hindu social hierarchy. 'Dalit' does not refer to a caste but suggests a 'state of being' in oppression, social disability and those who now cherish a hope of emergence. In the socio-political situation of caste-ridden country, the Dalit community stands for the one whose fundamental/human rights are severely violated. More than one-sixth of India's populations (about 160 million) are Dalits, located at the bottom of the caste system and face what is known as India's "hidden apartheid".

In an era where New Economic Policy is adversely affecting the social and economic interests of all weaker sections, depressed and disadvantaged sections, the nomenclature 'Dalit' can be applied in a very broad sense to all broken people and disadvantaged people. Traditionally oppressed Dalits, adivasis who are displaced due to development projects in their resource rich habitats, the other backward communities who all form a social majority "bahujans" have also be referred to as Dalits.

### II. HOW DOES THE CASTE SYSTEM MARGINALISE DALITS?

Societies are stratified on caste, class, elite, professional and occupational categories which correspond to their social position determined by status, wealth and power. The caste system of India has been described as the world's most elaborate and politically most documented system of stratification with its inherited inequality and the visible and violent practice of discrimination. The worst positioned in the Indian caste system are Dalits and adivasis. The system segregated Dalits from the rest to such an extent that they were denied even basic human rights.

*This social structure of stratification has the following characteristics:*

- 1. Inherent inequality*
- 2. Differential access to goods, services and opportunity*
- 3. People evaluate one another in terms of structural positions they occupy*

The caste system is linked to the natural resources, livelihood resources and in the Indian context it is intertwined with land economy and land based power relationships like feudalism.

## **Feudalism and caste:**

Caste relations were linked to caste feudalism and class structure. The feudalism in the context of caste created artisans and service workers and also created hierarchy among them. The priests and others at the top and scaling through goldsmiths, barbers down to weavers, washer men, leather workers at the bottom. The bottom level of artisan and service workers were seen as untouchable due to the polluting nature of their particular work such as handling leather, removing dead cattle from village grounds, roles in death and funeral ceremonies etc. The untouchable castes, which were performing the most essential tasks of removing the most polluting elements of the entire society, were considered the most polluting elements of the entire society, vis-à-vis the Brahmans' absolute purity.

In both the *Ryotwari* (peasant cultivator) and *Zamindari* (landlord) system, the untouchable service castes were also used as untouchable field servants (farm labourers). They were bound to the families of cultivators in a semi-slave manner.

## **Caste and economics**

Assigning different jobs to different castes resulted not only in division of labour but also the 'division of labourers'. The effects of the birth-based occupational distribution on different castes were entirely opposite in nature. While for the upper castes it was a divine privilege enjoying the monopoly of education, industry, trade, commerce etc. on the one hand, it spelt disaster for the lower castes on the other. This was because they were assigned the tasks involving only low paid/unpaid menial labour which was also considered impure, dirty and hence got stigmatized. In the absence of freedom of occupation, low earnings, implicit restriction on needs, and stigma on menial labour destroyed the economy of lower castes. As a result, being dependent on the upper castes for existence they remained socially outcaste, economically dependent, politically powerless and culturally subjugated.

## **III. WHAT ARE THE SOCIO-POLITICAL FACTORS DETERMINING HEALTH OF DALIT COMMUNITIES?**

World Health Organisation defines health as 'physical, mental, psychological and spiritual well being and not only the absence of disease'. This 'well-being'/health is socially determined by various factors such as access to resources, livelihood and freedom from discrimination.

## **Inequality – Discrimination – Denial to Resources (including health) - Social exclusion and structural oppression/violence**

Inequality (pre-determined low social position and status)



Discrimination



Denial to Resources:

- 0 Physical
- 1 Intellectual
- 2 Emotional/cultural
- 3 Economic
- 4 Natural: Land, water, rivers, forests etc.



Violence: (Physical, psychological, emotional, cultural and structural)

- **Access to Resources, Entitlements and Health:** Nearly 80% of Dalits live in villages and are still dependent on the others for their livelihood with meager purchasing power, chronic inadequacy of housing and without adequate resources and entitlements. The landholding scenario is an indicator to the entitlements of Dalits. In 1985-86 the percentage of marginal farmers among the Scheduled Castes was as high as 71 as against 58 for the population as a whole. Nearly 13% are completely landless. **(Source: NSS Round 37, 1982, Table on landholdings and Govt. of India, 1990b)** With the abandonment of land reforms in most states, even the prospect of land reform undoing the historical discrimination faced by Dalits in access to land has been denied.

### **The socio-economic profile of Scheduled Castes (All India)**

<b>S. No.</b>	<b>Indicator</b>	<b>Status</b>
1	Population (1981)	10.48 cores
2	Urbanization	16.00%
3	Literacy	21.38%
4	Agricultural Laborers	48.22%
5	Cultivators	28.17%
6	Average Status of Cultivators	Marginal
7	Industrial Employment	4.00%
8	Percentage of people BPL	50.00%
9	Bonded Laborers	66.00%

**Source: Govt. of India, 1990. Report of the Study Group Appointed During the VII FYP to look into the progress of the SCs and STs. New Delhi: Ministry of Social Welfare**

(B.L.Mungekar, 291)

- **Discrimination:** Discrimination based on caste affects, Dalit people's health in many distinct ways such as health status, access to health care, and quality of health service. Discrimination also takes the pernicious forms of social exclusion, physical and social



segregation of Dalit groups and individuals, and of the continuing and criminal practice of untouchability. Discrimination in access to employment (in terms of exclusion from employment in specific tasks, the rates of wages paid, and un-free work relationships, including bondage); lack of ownership of the means of production (including, most importantly, land); discrimination in access to price and non-price markets; and lack of access to public services results in denial to health and well-being.

Because of their social positioning, discrimination has taken the form of physical, psychological, emotional and cultural violence which have become part of the system legitimized by religious and social traditions. e.g. not having access to public places like temples, hotels etc. is a psychological violence. Physical segregation of settlements in villages is more often than not is forced living in the most unhygienic, water logged and low lying areas of the village. Besides, denial of access to land, good housing, conducive atmosphere is a systemic violence that is meted out to the Dalits and a basic denial of health and human rights.

Discrimination practiced against Dalit health personnel (doctors, nurses, ANMs, Anganwadi worker etc.) by the medical fraternity is also a matter of grave concern. The recent anti-reservation protest all over the country by the organized upper caste medicos is an indication of this deeper malaise. Medical education and medical fraternity needs to understand this unscientific and irrational approach and attitude towards Dalits.

***Belief in untouchability and the subsequent practice of discrimination are justified based on the Caste ideology which in turn is based on the acceptance of purity and pollution, hereditary transmission of qualities, and sanctions and legitimization given by religious traditions***

- **Social Exclusion:** Caste embodies symbolic devaluation and social exclusion. Discrimination which is the consequence of social exclusion with respect to resources, livelihood and public health facilities have had profound consequences. Defining certain sections as belonging to the lowest and despised category or not belonging to the social system at all, various forms of injustice are legitimised, including physical harm, sexual violence and economic abuse equivalent to slavery, brutality such as torching and axing Dalits to death, public humiliations like parading men and women naked, forcing them to drink urine and eat feces, etc.

Social systems in India continue to foster spatial segregation of population, with the untouchables confined to the margins of settlements. Access to the commons and community resources/goods (like drinking water/wells, etc.) and to basic services is often denied. With the structural imperative in the new economic policy to reduce public spending, these groups are finding themselves further excluded. This has direct effects on the life expectancy and health of these marginalised caste groups. They are more likely to suffer from malnutrition resulting in high mortality, morbidity and anemia.

- **Lack of Access to Education:** As access to education is very limited and the quality of education they get even if they go to school is very low. The drop out rate among Dalits and especially girls is very high. Hence what little health knowledge that our educational system provides is not available. They are victimized for their social status and develop inferiority complexes and this affects their confidence in accessing higher and special education.
- **Lack of Access to Health Care:** The access to and utilization of health care and related services is governed by the social status within the society. Caste based discrimination directly impedes equal access to health services by way of exclusion. The attitude of the health personnel, the untouchability practiced even by the health staff denies them access to adequate facilities and timely medical care. Ample evidence is available to show that anganwadi/ICDS workers, ANMs do not visit the houses nor touch dalit pregnant women or children. As the process of dismantling of the public health system and promotion of privatization of health care facilities is going on in an unchecked manner as part of the neo-liberal economic policy, it is highly unlikely that Dalits can afford any care with the consequent rising cost of the medical care.
- **Government's Apathy and Inaction:** The discrimination and denial of health care is hardly recognized as problems deserving attention. By and large, governments do not even collect, identify or track information on health disparities. In the Census, NSS or NHFS the disaggregated data on the morbidity, malnutrition, IMR, MMR and other vital human development indices are not available for Dalits.
- **Atrocities and Violence:** Discrimination against Dalit communities, sanctioned by societal dominant forces and legitimized by the cultural and religious practices take different forms of atrocities ranging from verbal abuses, physical assault, parading naked and forced consumption of urine or excreta, social boycott of the Dalit

communities to physical attacks on individuals and communities, grievous injury, torching and lynching to death of individuals and entire Dalit settlements, molestation and rape of women, etc. The worst atrocities against Dalits are in various forms such as murder, grievous bodily harm, arson and rape (Kamble, 1992). Although registered cases represent only a fraction of the actual atrocities committed against Dalits, it is noteworthy that between 1994 and 1996, a total of 98,349 cases were registered with the police nationwide as crimes and atrocities against scheduled castes. Of these, 38,483 were registered under the Atrocities Act, 1,660 were for murder, 2,814 for rape, and 13,671 for hurt. (National Crime Record Bureau). In other words, *these data show that about 134 crimes against Dalits were reported every day, and that, on average, three Dalit women are raped and six Dalit women disabled every day. These figures however are a gross underestimation because a large number of cases of sexual assault do not get registered.* At the same time, recent reports indicate that only 1 per cent of cases under the Scheduled Caste and Scheduled Tribes (Prevention of Atrocities) Act end in convictions. Even the killers in the shocking case of the lynching of five Dalits in Duleena in Jhajjar, Haryana, have not been punished. Five Dalits were burnt alive in Kambalapalli (Kolar dist; Karnataka) but justice has not been done to them. Increased social discrimination has been accompanied by new levels of reported violence: in 2000 alone, 25,455 cases, including 3,497 cases of grievous injury and 1,083 cases of rape, were reported.

In states like Bihar the organized atrocities of upper caste Ranvir Sena on Dalits is familiar news. In one of the largest of such massacres, on the night of December 1, 1997, the Ranvir Sena shot dead sixteen children, twenty seven women, and eighteen men in the village of Laxmanpur-Bathe, Jehanabad district in Bihar. Five teenage girls were raped and mutilated before being shot in the chest.

#### IV. WHAT IS THE CONDITION OF THE HEALTH STATUS OF DALITS?

Despite the fact that the Dalits are 'entrusted' with the responsibility of cleaning the filth of society, very little concern has been shown regarding their health. Not many studies have examined the socio-psychological dimension of stigmatization of Dalits and its impact on health.

- **Poorer health status:** Poorer health status, including higher morbidity, lower life expectancy and higher rates of infant mortality based on caste and also sub-caste. The discrimination and denial of health care is hardly recognized as problem deserving attention and governments do not even collect data disaggregated by caste to identify or to track information on health disparities. In India, the under five mortality among the Dalit children was 95 per 1000 live births, an excess of almost 25% over the national average. In Nepal too, life expectancy of the Dalits is 42 years compared to the national average of 58 years.

The reasons for dramatic health disparities are varied and complex. But caste discrimination against Dalits which is visible in social, political, economic and cultural forms is a major contributing factor to subject millions of people to poverty, unemployment, lack of proper housing and sanitation, greater exposure to unhygienic

environment, inadequate nutrition and low quality education. These are all determinants of health status.

A perusal of differentials in health status among socio-economic groups reflects upon the fact that Dalits have higher levels of mortality and malnutrition among their children compared to non-Dalits (Table 1).

**Table 1- Mortality and Malnutrition among Children**

<b>Indicator</b>	<b>Infant mortality / 1000</b>	<b>Under 5 Morality/ 1000</b>	<b>% Children underweight</b>
India	70	94.9	47
Scheduled castes	83	119.3	53.5
Scheduled Tribes	84.2	126.6	55.9
Other Disadvantaged	76	103.1	47.3
Others	61.8	82.6	41.1

*Source: National Health Policy 2001, Delhi Science Forum, Sake, New Delhi.*

Also evident from Table 2 is the fact that among children aged between 12 and 35 months, who received at least one vitamin A dose, 27% Dalit (scheduled caste) children were reported as against 34.8% non-Dalits. Among children aged less than 3 years, more Dalit than non-Dalit children suffered from acute respiratory infection and diarrhoea. (NFHS- 2, 1999).

**Table 2- Morbidity among Children**

<b>Groups</b>	<b>Vitamin A dose received</b>	<b>Acute respiratory Infection</b>	<b>Diarrhea with blood</b>
Scheduled Castes	27.1	19.6	2.9
Scheduled Tribes	26.0	22.4	3.7
Other Backward Castes	26.8	19.1	2.6
Others	34.8	18.7	2.1

*Source- Tables 6.14 and 6.16, National Health and Family Survey 2, 1998-9*

Seasonal epidemics causing higher mortality among Dalit scavengers are diseases like dysentery, malaria and tuberculosis. The residential quality of these people is highly conducive to sickness and disease. **The focus of five year plans has been to control communicable diseases but the other determinants of their health such as public health and access to health care services and access to the determining resources like land, water, housing, education, wages and**

**employment, equal opportunity, freedom from violence and harassment are important issues that need consideration at the policy and action level without which health will remain a mirage for Dalits.**

- **Low Quality of Health Care:** In a public health system which is already facing paucity of funds, inadequate supply of medicines etc. Dalits have to endure disparity in health interventions. The practice of irrational diagnostics and treatment, corruption and only being considered potential population for family planning programme Dalit communities receive low quality health care. In addition to the lack of access to health care due to various socio-political and economic reasons, the general bias in the mind of health personnel and the atmosphere of the health system both contribute to the low quality of health care that is offered to Dalits.
- **Struggle for survival and health:** Dalits are forced to do hard labour for bare and minimal subsistence. Including the marginal farmers among Dalits almost 70% of them are daily wage or agricultural labourers. Agriculture based wage work being a seasonal employment in agricultural fields with no work in most part of the year, they have less access to good food/nutritious food. In the agricultural sector the minimum wage is as per the Minimum Wage Act is not in practice. In many parts of the country the daily wages in season are Rs.30/- and lean season it is 15-20 rupees per day!). Constant increase in prices of essential commodities such as food grains and cereals while the wage revision or implementation of the Minimum Wages Act not happening has left Dalits very vulnerable to food insecurity, malnutrition and morbidity. This results in wholesale migration to urban areas to work where the occupational hazards just compound their health due to water and air pollution and unhygienic settlements. In the event of disease, very often they come too late to be treated and hence either the treatment is not possible or affordable. Many a time the health problems get complicated and huge debt is incurred as the public health institutions are malfunctioning and timely health care is not available to them.

### **Dalits among Dalits: Plight of other Vulnerable Groups**

The impact of caste discrimination and related intolerance has more severe implications on other groups within Dalit communities. People living with HIV/AIDS, mental illness, disability are subjected to severe forms of discrimination that denies them access to treatment and prevents them from obtaining jobs and participating in the life of the community in general and even Dalit community in general. The aged among Dalits do not have access to food, water, nutrition and medical care. From the estimated 40 million child labourers in India, 15 million are bonded labourers and majority of them are Dalits who work in slave-like conditions in order to pay off debt.

- ***Dalit Women:***

The situation of Dalit women is of greater concern due to her multiple identities. Dalit woman belongs to the oppressed caste and is a lower class person working as domestic

worker, daily wage laborer, agricultural laborer who also has to fulfill her role as a woman (wife, mother, sister etc.). The burden of triple oppression by caste, class and gender is the legacy of a Dalit woman.

Women's movements have hardly addressed the issue of the gender related oppression of Dalit women and most of these are homogenized as violence against women. Even within Dalit movements the issue of patriarchy, gender based violence, domestic violence, the issues of deserted women and widows are hardly addressed. The intensity of the oppressive situations that confront Dalit women is much severe and harsh than compared to their counterparts in the upper castes. High dropout rate and high illiteracy exists in Dalit women. The child marriage, child labour, devadasi system, exploitation of women and trafficking which result in prostitution, etc. are the endless problems that a large number of Dalit women have to face.

Rape is used as a political tool to subjugate the community and as a medium for retaliation. In a caste-conflict situation Dalit women are raped and subjected to heinous crimes and torture. In Vanenur village of Bellary district in Karnataka, a Dalit woman was paraded nude and was physically abused as the cause for a Dalit boy eloping with an upper caste girl. Targeting of Dalit women to make political statements in any conflict situations or in the issues of upper caste honor is a not an infrequent scene in the rural areas of the country.

Gender discrimination has an enormous multiplying effect on discrimination in health. They are subjected to sexual violence, denied of education and work opportunities, and discrimination in social and civic life all of which lead to impaired health status. Women, children, widows/single women, aged, physically-mentally challenged among Dalit women have to face the severest brunt of the system and denial of health care.

### **Health and Occupation Interlinkages- the Scavenging Community:**

The most significant factor in determining the health situation of any community depends on its socio-economic conditions. The essence of caste is characterized by the presence of hereditary groups in a hierarchy with Brahmins at top and Dalits at the bottom, and the bottom being forced to do unclean occupations (Srivastava, 1997). According to government statistics, an estimated one million Dalits are manual scavengers who clear feces from public and private latrines and dispose of dead animals (Human Rights Watch, 1999). The members of scavenging community engaged in what is known as 'special occupations' are more vulnerable to stress and diseases. The work conditions comprise of stench and foul smell, carrying the night soil on their heads, lowering themselves into manholes which emanate gases that not only have bad odours but are injurious to health too. Carrying night soil and cleaning toilets/ latrines every day is not a healthy job. It carries certain infectious diseases such tuberculosis, malaria and skin disease through exposure to filthy working conditions.

There are rules and legal provisions to stop manual carrying and cleaning of night soil. Parliament, in the Budget session of 1993, passed the “Employment of Manual Scavengers and Construction of Dry Latrines (Prohibition) Act, 1993” to abolish scavenging and put a ban on the construction of dry latrines and engage in or employ for or permit to be engaged in or employed for any other person for manually carrying human excreta. It lacks time limitation, though several states have followed the purpose of the bill as in Andhra Pradesh, Goa, Karnataka, Maharashtra, Tripura, West Bengal, Bihar & Delhi (Srivastava, 1997). Health is fundamental to national progress and more so for the people who are engaged in cleaning others’ filth at the risk of their health.

There are hardly any studies on Dalits and especially, scavengers, which describe the distribution and size of disease problems among them. Most Dalits engaged in ‘special occupations’ explore alternatives to cope with their working conditions and fall easy prey to the consumption of tobacco, paan and consumption of alcohol. The use of alcohol in heavy doses becomes a necessary part of their working conditions and thus for livelihood. Labelled as ‘special occupations’, they remain a complicated socio-economic problem and trapped in this web of poverty Dalits again fall prey to unhygienic coping practices which again adversely affects them. Paradoxically the dominant Indian society harbours in mind this unhygienic attitude against Dalits and their occupations and continues to look down upon Dalits which is a major hurdle for the liberation of Dalits. What Dalits essentially need is a “radical change of mental outlook” by Indian society (Chaplin, 1997).

## V. HOW DOES NEW ECONOMIC POLICY AFFECT THE HEALTH OF DALITS?

Dalits are among the sections of society that have been worst affected by neo-liberal reform. The collapse of urban and rural employment, and the curtailment of expenditures on and privatisation of health, educational and other aspects of social infrastructure have especially grave implications for Dalits. The dismantling of welfare state adversely affects the social, economic and political interests of Dalits. Expenditure cutbacks have further limited the scope of affirmative action through various government programmes. As a result of privatisation, there has been a decline in the availability of regular salaried jobs to Dalits and increasing share of Dalit workers has been forced to work as casual laborers.



Including the Adivasis who are displaced due to developmental projects in their resource rich habitats and other subsistent artisan communities, the Dalits form the social majority. The only support that Dalits had was from the state in terms of positive support from state reservations in education, occupation and elections. While the former two gave them opportunity to dignified life, the latter created structural opportunity for participation in democracy and decision making. However, with the shrinking public sector the levels of employment have decreased.

But nobody even ask us! This hurts us! We need  
**A World Where We Matter!**



Majority of Dalits are in the agricultural sector are landless labourers and a few of them are marginal farmers. However, due to the NEP agriculture itself is in crisis with over one and a half lakh farmers (mostly small farmers) committing suicide in the last 8 years. Besides that as the farmers engage mechanized harvesting the Dalits are losing jobs. The agricultural sector in which 75% Dalits were employed is in crisis and that creates more unemployed Dalits. While integrating into the global economy, caste-based institutions continue to determine economic advantage through religiously sanctioned segregation and ordering of occupations.

While job opportunities are less in the production sector, the service sector it is highly computerized, anglicized and technocratised. In the given situation of high illiteracy where Dalits are now beginning to go to the local medium schools the reach of service sector to majority of them is a distant dream. Some of the important issues among many others mentioned above faced by Dalits having a direct linkage to their well being/health are

- Denial of Access to land;
- Increasing food insecurity;
- Corruption and malfunctioning of Public Distribution System;
- Lack of job guarantee/opportunity;
- Dwindling public health system and denial of health care to Dalits;
- Withdrawal of State from social security sector.
- Commercialization of medical care and inaffordability of Dalits to access it;

- High chemical input agriculture has had the toll on the health situation of Dalit agricultural labourers;
- Less access to healthy and nutritious food and continuing malnutrition;
- Continuing low paid wage labour and the continuation of forced scavenging work;

India has one of the lowest investments in public health in the world. Worse still, during the nineties, the percentage of Gross Domestic Product declined from 1.3% in 1990 to 0.9 % in 1999. Public Health has been neglected since the liberalization of the Indian economy. One must illustrate the issue of Dalits in the context of the new economic policy based on the spirit known as 'privatisation' of all public sectors.

## **VI. WHAT ARE THE RESPONSES OF DIFFERENT SECTIONS TO THE HEALTH OF DALIT COMMUNITIES?**

Dalit communities is a culturally and socially a rich group with thousands of years of tradition and traditional knowledge. The Dalit community is the first in the history who experimented and had the knowledge of tanning and processing leather. Being farm slaves/farm workers a vast amount of knowledge with regard to agriculture was in the community. Being a community which has survived onslaughts from people, nature (droughts/famine) the community has strong coping mechanisms and survival skills. Many places we find them having knowledge of traditional medicines, crafts, plants, animals etc. Even while being denied access to any resource in the villages such as education, safe living conditions, water, public spaces etc. the community has survived and thrived. However we find along with other artisan communities the Dalit community is subjected to the attack of LPG.

- **What Dalits have done for themselves?:**

Dalit communities have organized themselves all over the country into strong people's organizations to struggle for their rights. This collective bargaining has been always with the state. They have also organized themselves into various cultural groups through which the cultural richness of the Dalit communities has been expressed. Some of the groups that have addressed these concerns among Dalits are

Dalit Sangharsh Samiti (DSS), Human Rights Forum for Dalit Liberation (HRFDL), National Campaign for Dalit Human Rights (NCDHR), Madiga Dandora ( A cultural organization of Dalits), Madiga Reservation Horata Samiti (MRHS) which demands the internal reservation among Dalits, Human Rights Watch, and scores of other Dalit and pro-Dalit organisations.

- **What others are doing for them?**

Many social action groups, citizens groups, human rights groups, peoples movements, such a PUCL, NAPM, PUDR and others have taken up the issues of discrimination of Dalits, violence against Dalit women, etc.

- **What government is doing for them?**

Government has chalked out number of welfare schemes for the development of Scheduled Caste communities. The SC/ST Commission has taken proactive role at the national level and state levels to implement these schemes. However, the usual malaise of corruption has again taken the toll of these schemes in their effective implementation and reaching to the deserving sections.

## **VII. WHAT NEEDS TO BE DONE TO ENSURE HEALTH FOR THE DALIT COMMUNITIES?**

While speaking of Health for Dalit communities, nothing short of considering health as a basic human right will be enough to make health accessible to Dalit communities. Dalit communities are those whose all rights are violated, even the right to live as dignified human beings. All the violations are linked to the violation of health right.

Different sections and political groups have placed the agenda of Dalits in their scheme of debates, discussions and action. However, besides the usual demands that are already placed before the various constitutional bodies such as land reforms, assertive action for employing Dalits in the private sector (including health), access to private educational institutions, the state machinery assuring the access to safe drinking water (from rivers, wells, water tanks etc.), housing, freedom from intimidating and coercive atmosphere of the dominant classes and castes etc. the following are specified:

### **ICMR/ICSSR has suggested the following among many to make possible health for all possible:**

- Integrated overall human development
- Improvement in nutrition, environment and health education
- ***The provision of adequate health care services for all and especially the poor and underprivileged:*** the aim of the programmes should be reduce poverty and inequality and also to improve the status of the poor and deprived social groups
- Government should provide disaggregated data for Dalits and Dalit women in the indicators of IMR, MMR, malnutrition, hunger deaths, anemia etc. as it does for education. Then only we shall be able to really assess the gravity of the situation of Dalits.
- Bring the existing movements for Dalit human rights, campaigns for different issues on Dalit issues, campaigns against atrocities into the larger canvas of health (human dignity as the basic component of well being).
- All kinds of practices of untouchability and discrimination like barring entry into hotels/temples/public spaces etc., manual scavenging, night soil carrying, atrocities and manifest violence in terms of physical torture, rape, molestation etc. should be taken up as the denial of health care and violation of health rights.

- Manifest efforts should be made for the representation of Dalit movements, Dalit social action groups or collective working for Dalit rights into the canvass of People's health movement.
- While recording access to denial to health care and all the unconstitutional practices, discrimination shown to Dalits in the health systems, the oppression meted out to them by the dominant classes in societies, anti-Dalit policies etc should be condemned and suitable protection measures should be enforced.
- Universal access to health care to all Dalits for all their health problems in the state institutions should be pressed for.
- Ensure access to water, housing facility, freedom from all kinds of atrocities, etc.
- Most of the time Dalits are considered impure because they eat beef. Beef is a very nutritious food and a large section of the world population eats beef and many a time beef is the only meat that is available for Dalits. All attempts towards Brahminisation of Dalits by imposing upper caste food culture on Dalits should be stopped and the food culture of Dalits communities needs to be respected.
- Concerted efforts are done by the right wing forces in the country to brain wash Dalits and to engage them in communal conflicts as front soldiers. For the health of Dalit communities, the conscientisation on the ploy of the Hindutva right wing ideology towards saffronisation and homogenization of cultures, and its implication on Dalit communities which will invariably result in deviation of the youth energy from struggling for the rights of Dalit communities is very essential.
- Appropriate implementation of the Employment of Manual Scavengers and Construction of Dry Latrines (Prohibition) Act, 1993 and proper rehabilitation of the scavengers is to be demanded.
- Strict implementation of Atrocities Act and Civil Rights Protection Act and to deal strictly with the social boycotts and other atrocious acts done on Dalits.

## CHAPTER II - HEALTH OF THE URBAN POOR

27.8% of India's total population lives in urban areas. That means 285 million urban citizens, as many people as there are in the United States totally. There are 4,000 cities and towns in India. About 300 cities have population over 1, 00,000. Seven cities have population more than 3 million

**31% of the urban population is poor (Source: Census 2001)  
Urban poor in India will be 200 million by 2025**

### Who are the urban poor?

Urban India is a study in contrasts: it contributes 60% of the country's national income. But 76 million urban Indians live below the poverty line, 21% of the urban population lives in slums, and 60% work in the unorganized sector, without any kind of social security (1).

Urban poor include day labourers, domestic helpers, small service providers, drivers, riksha pullers, hairdressers, vendors, beggars, street children etc. Some, however, work in factories or even as government employees at lower levels with wages that barely meet their needs. Most of them have migrated from villages in search of employment opportunities.

### Rural poverty and urbanization

Rural poverty is forcing millions of people from rural areas to migrate to urban areas in search of subsistence for their livelihood. When they reach the urban areas, the only place which is available for them to make their habitation is the already over crowded slums located in most places unfit for human habitation and lacking the basic amenities. The National Commission on Rural Labour reported that uneven development was the main cause of seasonal migration. The migration of rural population to urban areas has made cities densely populated.

### Identity crisis of the Urban Poor

The estimates of urban poor do not reflect the true magnitude, as significant proportion of urban poor is "un-accounted" for as they stay in unrecognized squatter-settlements, pavements, constructions sites, urban fringes, etc. Many of them lack basic documents of citizenship identity like their name in the voters list, ration card etc. National data such as the census, sample survey most often do not include them. Thus no information is available for planners to plan any service for them. They are denied of basic services for want of proper identity.



You have 24hrs to shift out of here. We are cleaning the beach for tourists.

**More than half of those living in urban slums had been living there for more than 15 years. About 20% had moved in during the previous five years. About 30% used to stay in a village before coming to the slum. About 20% slum households did not possess any document like ration card or voter ID-card (2)**

As per our records you do not exist in this world.



### **Who are they?**

Children who live or work on the streets are known as street children. Some of these children live with their families (who are also living on the streets). Other street children live and work on the streets but do not live with their families. The term can also include child labourers, sexually-exploited children, and war-affected children, who may also be forced to live or work on the street (3). Street children are subject to malnutrition, hunger, health problems, substance abuse, theft, harassment by the city police and railway authorities, physical and sexual abuse.

**UNICEF's estimate of 11 million street children in India in 1994 is considered to be conservative. Estimated 100,000 – 125,000 street children each in Mumbai, Kolkata and Delhi, with 45,000 in Bangalore.**

There are few interventions recommended based on the report from the consultation meeting, “A Civil Society Forum for South Asia on Promoting and Protecting the Rights of Street Children” in Colombo, Sri Lanka in December 2001. The report suggested measures for street children’s holistic mental and physical being and how government could play a significant role in fulfilling it.

### **Determinants of urban health**

#### **Poverty**

The vicious cycle between poverty and ill health is well documented in many studies. Constant ill health further impoverishes the poor. Unless the cycle is broken, the chances of the poor enjoying the basic health will continue to be in jeopardy.

**Over 400 million people in India live below the internationally agreed poverty line (living on less than US \$1 per day). This is one in three of the worlds poorest.**

The World Bank's definition of the poverty line, for under developed countries, like India, is US\$ 1/day/person or US \$365 per year, as per this definition, more than 75% of all Indians are, probably, below the poverty line. Poverty in India can be defined as a situation only when a section of peoples are unable to satisfy the basic needs of life. According to an expert group of Planning Commission, poverty line in rural areas is drawn with an intake of 2400 calories in rural areas and 2100 calories in urban areas. If the person is unable to get that minimum level of calories,he/she is considered as being below poverty line (4).

### **Malnutrition**

Malnutrition is a common problem where the poverty status is constant. Poverty status of families affects the children more. Based on re-analysis of National Family Health Survey 2 (1998-99) data by Standard of Living Index, 56.8% of less than 3 years old children (about 4.5 million), among the urban poor are malnourished. Poor living environment further adds to health challenges of slum dwellers: Inadequate sanitation, hygiene and water are a predominant feature of urban slums which results not only in more sickness and death but also in higher health costs, lower school enrollment and retention rates and lower work productivity. Poor living environment in urban slums therefore, calls for greater attention of service providers and coordinated action by the Integrated Child Development Services (ICDS) and other concerned departments.

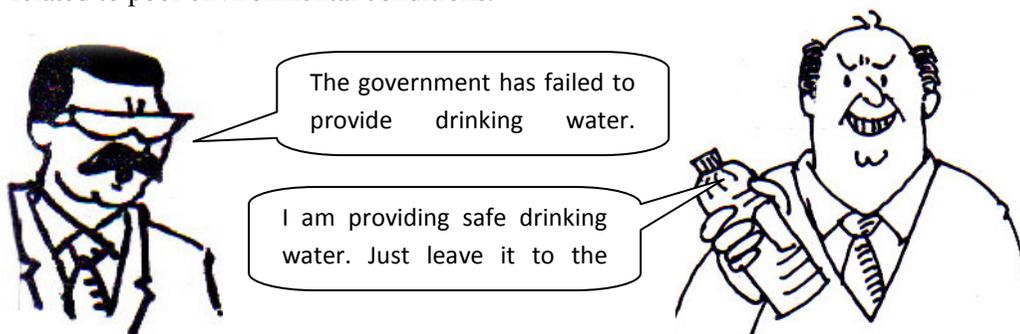
Another concern area is the availability of food grain. The population has increased from about 36 crores in 1951 to 103 crores in 2001. Despite the food grain production going up from 175 million tonnes in the 1980s to 206 million tonnes in the 1990s, the growth rate in the per capita availability of food grains has come down. The Planning Commission also has observed that that food consumption by the poor has gone down in the last 10 years. No wonder that the NFHS-3 data shows high rate of malnutrition across many states (5)

**The per capita availability food grain is about 460 gm which is below the recommended nutritional level of 575 gm. That is one reason why about 47 per cent of our children are underweight and our infant mortality rate, at 66 per 1000, is much**

**Most urban poor live in places that are overcrowded with poor sanitary conditions, not meant for human habitation; lacking facilities such as water supply, toilet facilities, and place for waste disposal. Some of these places are permanent and others are temporary, (UN Habitat, 2003)**

## Overcrowding, Lack of water and sanitation

The inadequate attention to rural development and present agrarian crisis are deteriorating socio economic conditions in the rural areas and force millions of rural poor to migrate to urban areas. As a result the existing slums dwellers face the problem of overcrowding in the existing places and new slums are created on place unfit for human habitation. Clogged drains, presence of rodents, lack of facilities for garbage disposal, stagnant water are commonly seen around the residential areas of the urban poor. Under these conditions the urban poor fall prey to many illnesses such as diarrhea, dengue, malaria, dysentery, cholera, jaundice and typhoid, which are closely related to poor environmental conditions.



Water supply and sanitation is the major concern particularly for the poor. A study conducted by the Jansahayog, an urban resource centre in Bangalore revealed that 10 out of the 14 samples collected from water source for the urban poor were unfit for consumption.

The urban poor also suffer from inadequate or lack of toilet facilities. In many places more people have to share a single common public toilet, which is poorly maintained. About one third of the population has no access to a lavatory, while another third share a latrine.

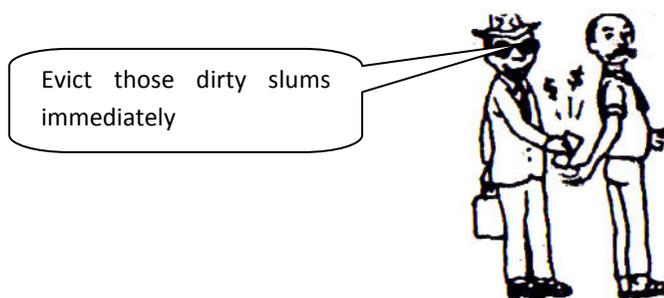
The growth of slums in urban areas is a manifestation of the inadequacy of basic amenities such as water supply, sanitation, electricity and other infrastructure facilities for the growing population. Lack of basic amenities in urban areas has a telling effect on the morbidity and mortality rates. Micro-level studies indicate high levels of morbidity and mortality among the slum population. Lack of sanitary and safe drinking water facilities, improper disposal of refuse and inadequate drainage system, and poor access to health facilities are some of the causes for this (6)

### Inadequate Housing insecure tenure of land

In slum households with one married couple, 44% of households did not have a separate room for the couple. In households with more than one couple, the problem was more acute (7).

**The city of Delhi has its own share of nearly 3.5 million urban poor out of which as estimated 52, 765 people are homeless. 90% of the homeless are productive and through their cheap labour subsidies the cities we live in (8) BOX**

There is a need to increase the supply of affordable housing to the economically weaker sections and the low-income category through a proper programme of allocation of land, extension of funding assistance, and provision of support services.



The problem of the urban shelter less and pavement dwellers has not been given the consideration that is needed for in a welfare or pro-poor polity, as seen from the lack of progress in the programme for the Night Shelter Scheme (9).

**The following schemes such as NSDP, SJSRY, VAMBAY, Night-Shelter, 2-Million housing scheme, AUWSP, Low-cost sanitation-etc are available from the central government for the urban poor. How easily are these schemes benefited the poorest of the poor and the neediest?**

## **Global Campaign for Secure Tenure**

### **Key principles and concepts**

1. Housing rights for all
2. Security of tenure as essential for city stability, human dignity and urban development;
3. Gender equity, to ensure active inclusion of women in development;
4. Partnership, as a means to ensure sustainable development through the participation of all protagonists;
5. Negotiated resettlements instead of forced evictions;
6. Transparent and open land markets to fight corruption and reduce speculation; and
7. Land availability to meet the needs of urban poor.

The UN Commission on Human Rights in its Resolution on Forced Evictions emphasized that, "the practice of forced eviction constitutes a gross violation of human rights, in particular, the right to housing. The Commission recognized that, "instances of forced evictions occur in the name of development (and) city beautification programmes" and cautioned; "state parties shall ensure, prior to carrying out any eviction, that all feasible alternatives are explored, avoiding or at least minimizing the need to use force and see to it that all the individuals concerned have a right to compensation" (10)

The Asian Human Rights Commission (AHRC) has received information about case of forced eviction from West Bengal, India. On 15 December 2003, the Kolkata Municipal Corporation carried out a forced eviction along the canal side settlements at the Bagbazar and Cossipore area. About 1,500 families were forcefully evicted without any rehabilitation plan. It is estimated that almost 75,000 people became homeless due to this eviction.

In Mumbai 80,000 homes were demolished between December 2004 and January 2005, rendering 300,000 people homeless. For majority of those evicted there was no advance notice, the evictions were violently carried out and their belongings damaged. Those evicted were not even offered alternative accommodation. This resulted in severe criticism from various quarters; the Chief Minister justified the brutal demolitions as the only way to convert Mumbai into a world-class city."

### **NHA recommends:**

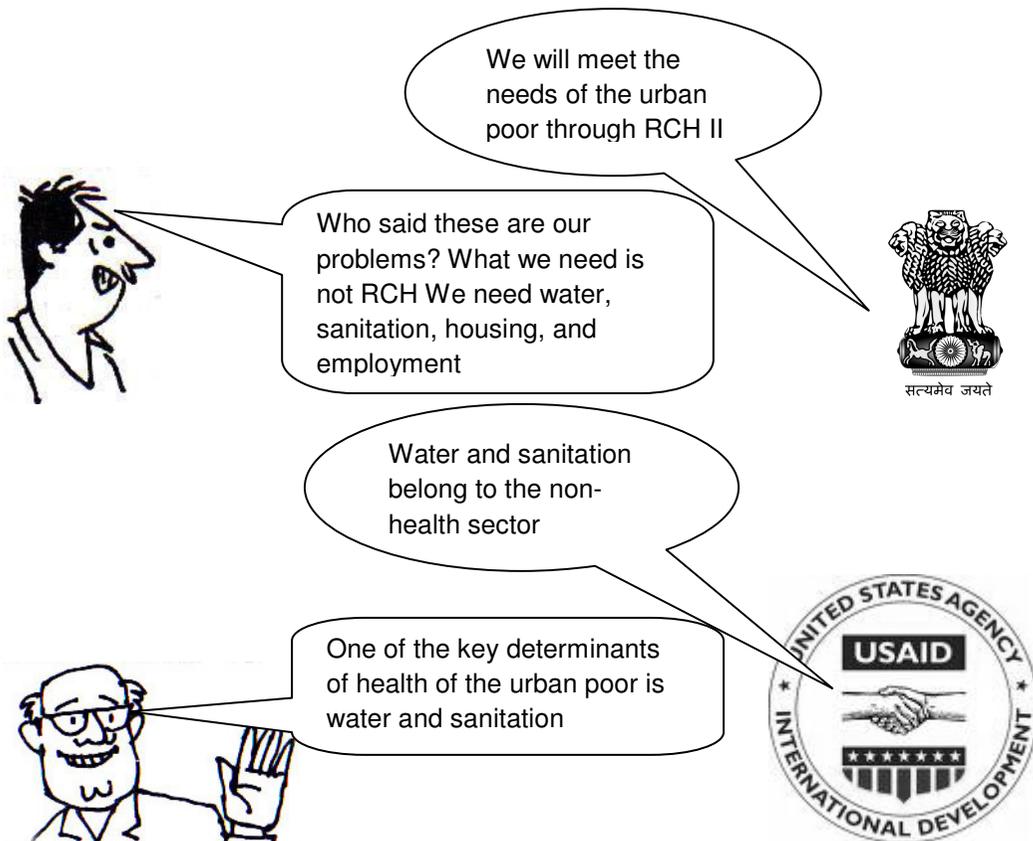
- **Mapping Migration:** Enhance national data collection and pool micro pieces of information from various sources to understand the scale/nature of migration
- **Identity & Entitlements:** Institution of a Migrant Cells, registration and Identity Cards; access to Public Services; cooperation between States / Ministries / Departments.
- **Labour Laws:** Time-bound implementation of minimum wages, social security and maternity entitlements; industry specific new legislations with Tripartite Boards particularly with regards to safety in places of work.
- **Childcare Services:** At worksites/through ICDS; special cadre of childcare workers; adequate budgets under current schemes/new legislations; replace "schemes" with a "per child norm" to allow flexibility; minimum wages to the worker.
- **Education:** SSA to mainstream the migrant child; options like mobile schools, bridge courses, etc. for migrant children; enforcing the law against child marriage as necessary pre-conditions to educating girls; review of the mid-day meal scheme.

### **Urban health services**

Urban areas are flooded with hospitals, nursing homes and clinic of various type and size which belong to both the public and private sector. The government of India appointed the Krishnan Committee in 1982 to address the problems of urban health. The health post scheme was devised for urban areas based on the recommendations of the Krishnan Committee. These services have been divided into outreach, preventive, family planning, curative, support (referral) services and reporting and record keeping. Outreach services include population education, motivation for family planning, and health education. In the present context, very few outreach services are being provided to urban slums.

The Health Post (HP) scheme was launched in 1983-84. A deputy director and joint director were assigned to urban health, but functioned chiefly to promote family planning goals [Verma and Bhende 1986]. In recent times the health planners propose one primary health centre for 100,000 population. This is against the Krishnan Committee report which said one centre for every 50000 population (11).

The 3,600 odd cities and towns of India with some 40 million people living in slums have to depend largely on private practitioners (mostly unqualified persons) for their health care needs. Out of the 3,000 plus urban local bodies in India only about 100 have been some semblance to a health care service while the rest have only a sanitary inspector or even a lower functionary to look after the health care system (12)



### ***Urban Health Challenges – NURM and NRHM***

The objective of the NURM was to strengthen democratic governance structure and decentralization in urban local government but without any clarity on how they plan to achieve it. The program has been critiqued for its following mandatory reforms:

- Public Private Partnership (PPP) models for development management and financing of urban health.
- Introduction of independent regulators for urban services.
- Rationalization of stamp duty to no more than 5% within five years.
- Repeal of the Urban Land Ceiling and Regulation Act.
- Reform of Land Control Law to stimulate private investment.

Did the **National Urban Renewal Mission** improve the quality of live of the urban poor?

The process of drafting the Mission was highly influenced by corporate interests in real estate, construction, transport and urban service sector lobbies. The entire Mission formulation and related actions have been orchestrated by agencies such as the World Bank and USAID which have a vested interest and long history of promoting neo-liberal developmental policies which include privatisation of water, electricity etc.



Where **National Urban Health Mission (NUHM)** takes us?

After launching the National Rural Health Mission (NRHM) in 2005 government of India realized that there is a need for concentrating on the ever growing urban population and hence the draft for NUHM was introduced in the public domain in 2008. This Mission like the previous one unfortunately, is promoting PPP, health insurance with no links of inter-departmental approaches for health. A public debate for its further improvement is required.

#### **In view of the above concerns NHA propose**

- Adequate attention should be given to rural development so that the rural population does not migrate to urban areas for livelihoods.
- When the rural poor are brought to urban areas by the contractors of the construction industry, basic necessities have to be ensured. Formulate standards of habitation that will ensure basic amenities such as housing, water and sanitation.
- Wherever slums/informal settlements are classified as Tenable, the ULB must facilitate the granting of tenure on all government occupied land and initiate acquisition proceedings and/ or negotiations on all privately occupied land in accordance with Section C.5 of the Draft Slum Policy
- Recognize the slums that are in existence for more than 5 years.
- There is a need to increase the urban infrastructure for health at all levels including big cities and small towns to cope with the growing urban population.

- Posts need to be created at various levels within the health department to ensure coordination, monitoring and review of all municipal bodies;
- All health posts should provide outreach services to slum and slum-like areas through the ANM and MPW;
- The recommendation of the Krishnan committee for a community health worker for population of 2,000 should be put into place;
- Ward committees should monitor and demand primary healthcare services from the health post system.
- There should be an intersectoral committee for public health for all municipal bodies.
- The provision of basic amenities for slum and slum like populations is required.
- Special provisions should be made for providing health services to pavement dwellers and temporary settlements.

New guidelines on the role and functioning of the health post system in view of an integrated and decentralised primary healthcare programme need to be developed and implemented uniformly across all the municipal bodies in the state;

There needs to be integration of all vertical programmes (such as TB, malaria, HIV/AIDs) with the primary healthcare system in urban areas. Unless there are attempts to correct the key determinants of urban poor's health like water, sanitation, housing and employment, it is unlikely to provide a healthy life to urban poor. Unfortunately the thrust of whatever limited healthcare services provided to urban poor is with a limited focus on RCH services in order to achieve family planning services.

## **CHAPTER III - COMMUNICABLE DISEASE CONTROL PROGRAMS**

Most of the problematic features of the healthcare system described above are reflected in the field of communicable disease control. A study of India's experience with communicable disease control clearly shows the limitations inherent in a narrow biomedical approach. We have been attempting to control diseases, while ignoring their social and environmental determinants. Continuing political neglect of the healthcare system and disease control programs has compounded the problem. The period since the 1980s has seen stagnation in many epidemiological indices as well as re-emergence of many of the communicable diseases. This period was characterised by the increasing burden of malaria, continuing burden of tuberculosis with very little impact despite great effort in the National Tuberculosis Program, increasing number of epidemics that were inadequately tackled, and epidemics of leptospirosis and arboviruses (especially dengue) and more recently Chikungunya and Avian flu, and the newly emerging HIV / AIDS.

### **What is Responsible for these Worrisome Trends?**

While the pattern of causation and spread of communicable diseases is well understood, this knowledge has not been adequately applied for their overall control. Communicable diseases are related to a complex set of factors, and cannot be explained adequately by simplistic linear models. The health of a given community is not determined merely by the presence of genes, germs, toxins or influence of healthcare services. Rather it is also influenced by larger social, economic, political, cultural contexts. In other words, the health of a given society is closely linked to the model of development that is followed. But health planners and professionals sitting in capital cities continue to largely ignore the social, economic and cultural contexts of people's lives. There has been a consistent choice of vertical programs over more 'horizontal' and people centered approaches in an attempt to tackle what are essentially social problems by means of a focus on technical fixes. This approach has not only ignored local contexts but also led to a consistent neglect of the general health system, which is crucial to addressing the felt needs of the people, as well as to provide a basis for implementing any other health program.

### **Why then, have the Vertical Programmes still been Promoted?**

The vertical programs have been attractive to the political leaders and bureaucrats for a number of reasons.

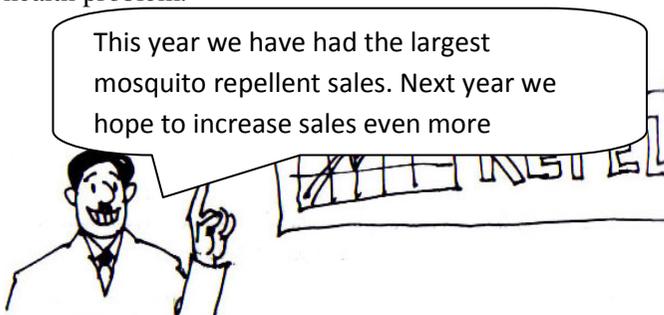
- They were expected to give spectacular results in a short time.
- This approach was assured support from international agencies and western countries.
- This approach offered a simple and less resource-demanding alternative to establishing a network of permanent health services to cover vast populations of the country.

- It avoided the awkward questions of poverty/inequity inefficiency etc. and thus continued the socio-economic status quo.
- Vertical programs are more easily quantifiable and definable with most components being in the planners 'control', this gives a sense of power and security to most planners.
- Vertical programs also have a higher probability of 'achieving targets' in the short term, though their effectiveness and sustainability in the long term is questionable.

In this process, finally the programme planners are left trying to balance two kinds of pressures. On the one hand, they have to respond to the international donors and political 'need' to do something while not questioning the status quo too much. On the other hand they have to face the deep-seated health needs and aspirations of the people. We will briefly discuss the control programmes for four major communicable diseases - Malaria, Tuberculosis, Leprosy and HIV/AIDS - as examples of this contradictory approach before suggesting the outlines an alternative approach.

## Malaria

In India we have had nearly 60 years of malaria control programs under different names - from a 'Control' program to an 'Eradication' program, to an 'Anti-Malaria' program and now a combined control program for vector-borne diseases. However these programs have all been characterised by a limited bio-medical-technological understanding and approach to malaria. Even though there were early successes in the immediate post independence period, and India has contributed very significantly to the global knowledge base of malaria control, we seem to be losing out in tackling the disease, and one perceives a sense of defeat in the way malaria is seen as a public health problem.



The current situation is characterised by:

- An increasing proportion of *P. falciparum* all over the country accounting for almost all the deaths and severe morbidity
- An *increasing incidence of drug resistance* to the routinely used chloroquine, which also is leading to increasing morbidity and deaths
- Highly centralised mosquito control program centered almost entirely on insecticidal effect of DDT has been rendered largely ineffectual by widespread resistance among mosquitoes to DDT

This has resulted in *recurrent focal out-breaks* that reflect the deteriorating environmental situation as well as the lack of surveillance and the absence of strong general health services.

These outbreaks are linked to specific *eco-types of malaria*. Both of these aspects of the current malaria situation are briefly analysed below.

An increasing number of focal outbreaks accompanying the emergence of specific ecotypes characterise the present situation of malaria in India. It is also well recognised that the number of malaria cases in India is grossly underestimated by official studies and there could be more than 18 million malaria cases and around 130,000 malarial deaths every year. *Estimates made by many malaria researchers range from between 10 million to over 30 million cases annually, which is anywhere from 5 to 15 times higher than the official estimates*. According to the WHO the true malaria incidence is thought to be 11 to 15 million cases in India which represents 74% of the malaria cases in this (South-east Asia) region.

The problems due to inability to tackle the germ and the mosquito are all compounded by an ineffective primary healthcare system. Prevention of malaria related morbidity and mortality critically depends upon a system of early diagnosis and prompt rational treatment, and community based control efforts, which should employ a combination of measures that are feasible and acceptable. Early diagnosis is a distant dream in a system where the malaria slides are reported weeks later, early rational treatment is out of bounds for people living in rural and tribal areas who are forced to access irrational care delivered by informal practitioners.

***An estimated 74% of the malaria in South-east Asia region occur in India***

Control efforts are only nominal in a situation where half-hearted DDT spray is all there is to speak of. The other feature in the period of resurgence has been the emergence of specific 'ecotypes' of malaria, esp. in the 1990s. These ecotypes essentially represent *disturbed ecosystems presenting as high malaria incidence foci*: these include '*Urban and peri-urban malaria*', '*Irrigation malaria*',

*'Forest malaria*', '*Migration malaria*' and '*Tribal malaria*'. It is not difficult to understand that a model of development based on increasing volumes of massive seasonal migration, especially from tribal and forested areas, with migrant workers living and working in extremely An estimated 74% of the malaria in South-east Asia region occur in India (WHO) rudimentary conditions in urban and peri-urban areas is directly responsible for the epidemiological features of many of these interrelated ecotypes. Similarly unplanned expansion of irrigation, without health impact assessments or measures to prevent water logging and vector breeding, present another facet of agricultural development that is taking its death toll in terms of outbreaks of malaria even in areas like Rajasthan where the disease was previously virtually unknown.

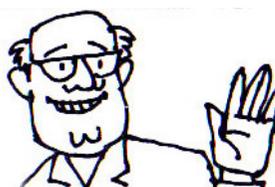
What is less commonly recognised is that the burden of morbidity in these ecotypes is heavily skewed towards those populations, which are already marginalised: Adivasis (tribal) communities, seasonal migrant workers, agricultural labourers and peasants directly engaged in agricultural work. Even though the linkage between mortality due to malaria and poverty / acute hunger was demonstrated almost 75 years ago through some very elegant epidemiological analyses, it has not entered our consciousness nor has it informed our control strategies. This is

despite definite evidence that the prevalence of malaria is higher in states and communities with a higher level of poverty.

## Tuberculosis

India is the country with the largest number of TB cases in the world accounting for nearly one-third (30%) of the global TB burden. In India itself there are an estimated 2 million people detected with tuberculosis every year, and around 4 lakh deaths occur yearly due to the disease, this number having remained more or less unchanged since Independence! The total number of patients with

Here's the deal buddy. Sign o the DOTS and we will give you a \$750 million loan.



pulmonary tuberculosis has been calculated at a staggering 17 million patients. These rates have remained more or less stagnant from the time of the first studies done as far back as 1954-58.

The National Tuberculosis Program that was introduced in 1962 was based on a broad socio-epidemiological and people centered approach to the problem of tuberculosis. Research had clearly shown that nearly 60 - 70% of patients with symptomatic tuberculosis were indeed visiting the health services but were being sent back with symptomatic treatments and cough mixtures. Consideration of tuberculosis as a problem of suffering (Felt Need Approach) and patients' recourse to general health services provided the basis for integration of NTP with the general health services. Thus NTP was designed to "sail or sink" with general health services [13].

The experience of the TB programs teaches us that inspite of there being a multisectoral inputs in the development of the NTP and integration with the general health system, it has failed in achieving its objectives, since the general public health system itself was systematically neglected in the continuous adoption and prioritization of vertical programs, especially the family planning and the immunisation programs. The sinking state of the general public health system has taken the Tuberculosis Control Programme along with it.



This programme has an apt name: DOTS – Deniel of Treatment to the Sickest!

To illustrate, a Facility Survey carried out by the IIPS showed that out of 7959 PHCs surveyed across India, only 46% have a laboratory. In states like Assam, Bihar, Madhya Pradesh and West

Bengal, not even 20% PHCs have a laboratory. Only 39% of PHCs have a lab technician, essential for any functional case detection process.

While there has been great fanfare in the adoption of the Revised National Tuberculosis Control Program, and claims of great success, experience over the last few years have raised some serious questions. The exclusive focus on the 'Directly Observed' part of the strategy (commonly known as DOTS) is being increasingly questioned. Recent studies have shown a very high incidence of inappropriate care and rejection of patients on the basis of their being 'non-ideal' candidates, who will spoil the statistics. Hence people without permanent addresses and migrants may not be enrolled under DOTS despite their definitely needing care. Then the somewhat better cure rates under DOTS could be related mainly to the regular, adequate availability of the required drugs (often not available in the general programme) and selection of 'better patients', rather than justifying the strategy of treating patients like irresponsible children who need to be 'observed' each time they swallow a tablet.

Further, the increasing proportion of strains showing resistance to single and multiple drugs does not portend well for the overall situation in India. The lack of standardisation of treatment regimes for TB in the private sector is a major cause for this situation; this is related to the larger problem of lack of regulation of private providers. Along with this, the link with HIV/AIDS means that there will be an ever-increasing number of patients in need of care. It is thus quite clear that the RNTCP, like every other such programme, depends for its success on a well functioning, sensitive and properly outreaching public health system.

## **Leprosy**

Leprosy has been declared eliminated as a public health problem in India on 31st December 2005 as it is supposed to have reached a prevalence of less than one per 10,000 populations. In an unprecedented situation perhaps without parallel in the history of public health, a disease has been declared eliminated in the country which is home to two thirds of the cases, by using a faulty epidemiological measure and altering the definition of a case, and by the simple act of decreasing the intensity of detection of cases. Elimination has been attained even as new case detection rate remains unchanged in India. The goal has been achieved by the simple expedient of moving the goalposts! This experience of 'eliminating' leprosy might embolden the government to eliminate virtually any kind of disease, however this statistical and programmatic chicanery has grave implications for the lakhs of patients with leprosy who shall suffer the consequences with continued pain, stigmatisation and disabilities.

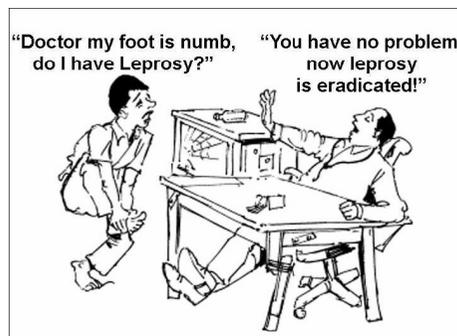
The 'elimination' of leprosy on the auspicious date of December 31, 2005 seems to have been achieved by widespread manipulative means. Examples include:

a) The National Leprosy Eradication Programme (NLEP) had stopped registering patients with single skin lesions by 2005 on the grounds that since experienced healthcare workers were not

diagnosing leprosy any longer, there was a risk of other skin diseases with single skin lesions getting diagnosed as leprosy! Some patients receiving treatment for a single skin lesion do not appear in end-of-year prevalence figures at all.

b) There was a shift from active case detection (going into the community and finding out patients) to passive case detection (sitting in the clinic and waiting for patients to come) with an expected drop in case detection rates given the fact that most leprosy in our country occurs among resource-constrained people in some of the less developed states with poor public sector medical facilities.

The declaration of 'elimination' of leprosy has successfully eliminated leprosy from the consciousness of doctors, if not eliminated the disease from the country. Health education material on leprosy, which was never abundant, has now completely disappeared. This has led to a decrease in the level of awareness about the presenting symptoms and signs of leprosy in the general population. Coupled with a poor awareness of leprosy on the part of doctors and the cessation of active surveillance, this is causing several people to present for care for the first time with already established deformities or anaesthesia.



The following steps are suggested to tackle this highly problematic situation:

1. The leprosy control programme should be re-instituted, at least in the following states that are home to nearly 95% of all leprosy patients in India:

**East:** Jharkhand, West Bengal, Orissa, Bihar

**Central:** Chhattisgarh, Madhya Pradesh

**South:** Andhra Pradesh, Karnataka, Tamil Nadu

**North:** Uttar Pradesh

**West:** Maharashtra, Gujarat.

2. Active surveillance in the community should be resumed, to ensure early detection of patients who are at risk of developing nerve deficits and also for reducing the transmission of the disease as much as possible.

3. Doctors in the public health system should be empowered, at least in the high-endemic states, to diagnose leprosy in the presence of the cardinal signs without having to wait for confirmation by the District Leprosy Officer (DLO). Currently, even dermatology faculty members in the local medical college have to wait for the DLO to confirm their diagnosis of leprosy.

4. The slit-skin smear should be given its due place in the diagnosis of leprosy, especially since this is invaluable for diagnosis of patients with early lepromatous leprosy.

5. We need to implement health education pertaining to leprosy through all possible media including radio, television, newspapers, and posters if we are to expect patients to present early on their own. There is need for increased awareness of pure neurotic leprosy without skin lesions both among the lay public and among doctors since a patient with pure neurotic leprosy will not visit dermatology OPD, unless he or she is possessed of a very high level of health awareness.

6. There is a need to ensure a positive outcome of treatment in terms of intact neurological function and freedom from deformities. All patients must be followed up after the completion of treatment.

7. Multi-centric trials should be supported to discover shorter and more effective chemotherapy regimens and for finding alternatives to steroids for curbing nerve damage.

## **HIV / AIDS**

Starting with the first case, detected in 1986, today, HIV has been detected in 29 of India's 32 states and territories. The epidemic is considered generalised (with the prevalence amongst pregnant women attending antenatal clinics being more than 1%) in six states – Andhra Pradesh, Karnataka, Maharashtra, Manipur, Nagaland, and Tamil Nadu. The National AIDS Control Organisation of India (NACO) estimates the number of people with HIV in India at 5.1 million in 2004. India is considered to have the second highest number of people living with HIV/AIDS in the world after South Africa.

HIV / AIDS is deeply symbolic of the collective malaise our society faces in the era of globalisation and liberalisation. It has been said with justification that HIV / AIDS is a development issue, that HIV / AIDS is a resurgent infectious disease, that HIV / AIDS is a public health crisis, and that HIV / AIDS is a major rights issue for a range of people whom this problem impinges upon. Keeping these and other dimensions in mind, no sweeping generalisations or vertical solutions are likely to be able to address this problem in its entirety.

Neither exaggeration nor denial is likely to serve the cause of tackling the problem effectively. The complex and multidimensional nature of the problem requires among other things, an approach that can grasp the myriad socio-economic processes fuelled by the process of globalisation-liberalisation responsible for the emergence and spread of the epidemic, the health system crisis that needs to be urgently addressed in order to present an integrated response to it, the range of socio-behavioural factors that need to be addressed for prevention, and the rights of affected persons to comprehensive care and social acceptance as part of a larger vision of health related human rights.

Of the major modes of spread of HIV - sexual contact, mother to child transmission, and through infected blood (transfusions and intravenous drug use), in India, the predominant mode of spread is assessed to be through sexual contact (80-85%), while the other 15% is accounted for by the other modes. Interventions to control the spread have therefore, concentrated on these three modes and have been linked with a verticalisation of the program. Efforts are concentrated on

creating awareness of the disease, safe sexual practices and distribution of condoms. Certain measures have also been recently initiated to provide Anti Retroviral Therapy (ART) to people suffering from HIV from a few specific centres. One specific point that needs to be considered here is that HIV spread through unsafe injections (a widespread and common practice, especially in the private sector in rural areas and urban slums) has hardly been studied systematically, and remains neglected. At a broader level, most of the existing approaches fail to take into consideration the other key determinants that lead to the spread of HIV: socioeconomic factors such as poverty, lack of education, unemployment,

**Marginalisation of women, development concentrated in urban areas, migration patterns, national debt and similar factors.**

In response to indebtedness and as part of the globalization process, governments in developing countries have been forced to increase export-oriented industrialisation and to reduce government expenditure. The model adopted for economic growth has led to the growth of employment in urban areas. On the other hand, public investment in the agricultural sector has been neglected with growing impoverishment of the rural toilers. This combination has brought about increased migration from rural communities into the cities. Long periods of separation from families, loneliness, alienation and work related pressures often drive people into high-risk behaviors, including use of drugs and alcohol and multiple sex partners. Mobile populations like migrant labourers also become intermediaries for infection to spread to other geographic locations as well as back to their spouses. Poverty and unemployment also drive women into transactional sex, again involving multiple partners and usually reduced negotiation power for safe sex practices.

A completely biomedical approach to tackling AIDS therefore can only hope to deal with the 'iceberg' of infected people or so called 'high risk groups'. Even though awareness drives and condom distribution are seen as preventive measures, these initiatives fail to address what drives people into vulnerable situations exposing them to unsafe sex in the first place. Unless there is a questioning of the developmental processes and attention is given to access to healthcare, education and food security for socio economically vulnerable sections of the population, there is little hope that the roots of the epidemic can be attacked.

A vertical emphasis on HIV / AIDS care as an additional measure might be justifiable where well-functioning healthcare systems already exist. But in countries where basic healthcare is not ensured, prioritizing HIV/AIDS care in isolation will not only be met with lack of success in the public health sense; it may also jeopardise the struggle for basic healthcare by sidelining it and making it appear less relevant. Ensuring a well functioning public health system at all levels – including functioning laboratories for detection, peripheral hospitals capable of treating patients with common opportunistic infections, well functioning larger hospitals capable of treating all aspects of AIDS, and a well functioning system for health education - is an essential prerequisite for HIV-AIDS control. These cannot be achieved just by pouring more and more funds into an isolated programme. It is worrisome that while all other communicable disease control disease

programmes are being integrated under NRHM, HIV-AIDS remains a stand alone vertical programme, perhaps due to the insistence of its influential donors.

If we look at the need for availability of anti-retroviral In addition to ensuring access to diagnosis and right to treatment of opportunistic infections and HIV infection, special attention needs to be given to the protection of rights of people living with HIV-AIDS in the context of the social impact of HIV infection. This includes the right to employment (important judgments exist protecting people from losing a job due to HIV status), right to education for HIV positive children, and property inheritance laws, which are of vital importance to women whose husbands, have died of AIDS and who have been thrown out by their families. The latter mentioned, law is of great importance in the Indian context where women are often married to infected men with the intention of care giving during the period of illness, and are deserted by the family upon the death of the man. The woman is often left without any property and by then is herself infected, left with no support in the face of a fatal and stigmatizing illness.

### **Towards an Integrated Approach to Communicable Disease Control**

The above discussion of the three major communicable disease control programs highlights the following major points:

- Vertically designed disease control programs that fail to acknowledge the complexity involved in the causation of disease, and that are designed in isolation from the reality within which people live - may have short term gains but cannot be sustained nor do they provide long term benefits. There are certain inherent problems in the approaches adopted to control certain communicable diseases - such as the Pulse Polio strategy for Polio Eradication - which have been discussed in a separate booklet.
- Failure to develop general health services, which need to be the basis for any interventions tackling particular diseases, will only lead to the failure of vertical, bio-medical interventions.
- To really control disease / prevent unnecessary burden one has to evolve programs that tackle the determinants of health and socio-ecological factors, in addition to providing cures and interventions that affect the immediate causes.

The following are a few suggestions towards a more integrated approach:

- Cure and control of communicable diseases, like any other disease should be seen as a fundamental human right of communities and individuals rather than as a favor by the government on 'beneficiaries'.
- The strengthening of the general health services needs to be seen as a priority as it both fills an urgent need of the people as well as being a foundation for the introduction of any further interventions.
- Any disease control program needs to tackle the determinants of health, while addressing the curative aspects as well.
- Given a human rights approach and the importance of the context and the complexity of the issue, people and communities have to be actively involved in all stages of planning, implementing and monitoring and evaluating.

As the ICSSR / ICMR report says, there are no short cuts, mere expansion of the present services is not going to solve the problem, what is needed is a radical restructuring of the services, placing the people in the center. 68

## **CHAPTER IV - Mental Health in India – An Overview**

### **1. Introduction**

The Alma Ata Charter in its definition of Health, which is state of OPTIMUM well being, includes Mental health.

Mental, behavioral and social health problems are an increasing part of health problems in the world and in India too. Though the burden of illness resulting from psychiatric and behavioral disorders is enormous; it is grossly under represented by conventional public health statistics, which lead to focus on mortality rather than morbidity and on being dysfunctional. The number of people with mental illness will increase substantially in the coming decades. It is seen that there is an increase in the number of young adults with mental disorders, and 50-75% of mental disorders begin during youth. Secondly, there has been substantial increase in the geriatric population having mental health problems, as the life expectancy is increasing. Thirdly, social factors which are established risk factors are also causing a change in the rate of depression seen in all age groups. Besides depression anxiety & Stress are also affecting children ,the causes being different from adults

Mental and behavioral disorders account for 12% of the global burden of disease. It is estimated that nearly 450 million people suffer from a mental or behavioral disorders in the world. Nearly 10 % of disability adjusted life years (DALYs) across all age groups are due to depressive disorders, suicides and alcohol related problems. Depression ranks third among men and second among women, yet mental health budgets of most of the countries are less than 1% of the total health expenditure. Mental disorders also kill in many indirect ways such as suicides, worsening the outcome of physical illness, medical complications and injuries related to alcohol abuse (i.e mental disorders as a risk factor for other health problems),unhealthy lifestyles and so on.

### **2. Ground realities**

#### **2.1 Demographic Characteristics**

India is a country with an approximate area of 3287 thousand square kilometres (UNO, 2001). Its population is over one billion and the sex ratio (men per hundred women) is 106 (UNO 2004). The literacy rate is 68.4 % for men and 45.4% for women. The proportion of population under the age of 15 years is 32 % and the proportion of population above the age of 60 years is 8%. The life expectancy at birth is 60.1 years for males and 62 years for females. The healthy life expectancy at birth is 53 years for males and 54 years for females.

## 2.2 Prevalence

A majority of the classical psychiatric epidemiological studies in the last four decades have been population based, focusing on general psychiatric morbidity in a small to medium population. From these house-to-house surveys, it is found that:

- An estimated 1 percent of the population, including children suffer from severe mental disorders.
- Five to ten percent of the population are reported to have common mental disorders.
- 15 – 20 % (in some studies it is 40 %) of the people approaching primary health care centers, general hospitals or private clinics for general health problems requires psychiatric assessment and evaluation. Some of them are not aware of it. They think and believe that they have some physical illness, and take various methods of treatment for relief, often in vain. Some of them are not aware they suffer from a biomedical mental illness, but they are aware that their symptoms are related to stress. In most other cases, the morbidity is unrecognized by doctors who treat the condition with symptomatic drugs .

If this figure is projected in India, there would be more than ten million people suffering from severe mental illness, and the figures for common mental disorders would be five to ten times that of severe mental illness. In addition there are issues related to suicide, substance abuse and mental disorders in children.

## 2.3 Mental Health Care

Mental health care has always been influenced and determined by contemporary beliefs, and India is no different. Traditionally, mentally ill people were often cared in temples and religious institutions, based on the principles that mental illness is a form of spiritual affliction and could thus be cured by religion. Superstition with inadequate mental health services in the community makes subjects people with mental illness to various harmful treatments. Often, certain treatment practices by black-magicians, village quacks, witches and physical abuse in the name of treatment can have harmful effects on the people with mental illness. They are kept outside the margin of the community by being chained, locked in rooms, found wandering on the streets, or staying for ever in closed wards of asylums, hospitals, etc. Bhoot mela in Chincholi in M.P., Pingalwada in Rajasthan are examples of societal responses to mental health problems While the situation described above is mostly applicable only for the rarer, severe forms of mental disorder (e.g. psychotic disorders) the vast majority of mental disorders are either managed at home or through primary care

## 2.4 Stigma and Discrimination

A large section of people with mental illness are still locked inside their houses without any treatment, because their family members do not recognize the illness or they find it embarrassing

to be recognized as family member of a mentally ill person, who are commonly called as 'mad'. There is also a fear that they would be victims of disgrace and indignity and thereby lose the status or acceptance they enjoy in the community. The stigma is so tremendous that people feel ashamed and deny the illness. Therefore, the first and foremost element that shrouds the realm of mental illness is stigma attached to it. The very thought of some one in the family having a mental illness is a big shock and they do not want to believe it.

Due to stigma attached to the families, people with mental illness become the victims of discrimination and human rights abuse. The discrimination is seen from the family members and goes right up to the policy makers and state authorities. The attitude of the public is often, "*who cares about what is done for people with mental illness*". People with mental illness have been treated as second-class citizens with no adequate facilities given, either at the state or the central government. As a result they face chronic ill health, and are seen as an economic and social burden to the community, leading to social destitution. Soon families lose hope and are left to the mercy of others.

The sheer drudgery of much of our work leads to serve physical and mental health problems.

We face not only occupational hazards but also other forms of overt and covert harassment including sexual harassment!

We therefore suffer mental agony and psychological stress and strain. This endangers our self respect and sense of dignity.



The demands for dowry and the mental torture associated with it is the single most important gender related cause of Exogenous DEPRESSION and anxiety. This has been responsible for suicides by young married women, who prefer dying to living a life of torture, with NO HOPE OF ESCAPE. The mental torture faced by childless women and those who "FAIL" to produce a male child has remained unaddressed. Rape & sexual harassment of girls & women & their sense of feeling "POLLUTED FOR LIFE", thus scarring many lives & therefore 'unfit to live' has scarred many lives, when it should be the rapists who should be made to feel the shame rather than the victims.

## **2.5 Human Rights Violations**

People lock or chain their kith and kin under pressure from others, due to helplessness and ignorance. This also happens in hospitals, asylums and special homes. It is grossly inhuman. Violence against women is a public health concern in all countries and especially women with mental illness are often subjected to physical and sexual abuse.

## **2.6 Existing Laws**

As per the law, a person with mental illness cannot sign any documents of sale, purchase, lease or any contract. The act is silent on these issues during the lucid moments or stabilized stage. Family members, mostly brothers, take undue advantage of this clause to deny property rights to the person with mental illness and enjoy all the property.

Marriage and Divorce Act also permits legal separation of life partners if one of them is found to be mentally ill (certified by a psychiatrist). Generally in rural communities men are permitted to marry for the second time if his first wife is suffering from any disease like mental illness, epilepsy and so on. On the other hand if a married man becomes mentally ill, the community insists that the wife continues to be the caregiver. If a family has a person with mental illness, getting life partner for a boy or girl from that family is almost next to impossible because of the stigma, as it is seen as a family illness. There are occasions where they hide the information and problems erupt after the marriage. It is also common that a close relative gets pressurized to marry such a person.

Mental Health Act has been misused by many men to dump their perfectly normal wives, by getting them falsely certified as mentally unsound. Many a time they pay the doctor to provide them with false certificate. The husband is then free to remarry for “another round” of dowry or simply buy his freedom after getting rid of his wife.

Stigma also affects health care insurance - many companies exclude mental illness from their cover.

## **2.7 Social Determinants**

Poor people with mental illness are not only vulnerable due to their condition, but also the vulnerability brought about by poverty, which is related to their condition. One of the main reasons that people find it hard to accept people with mental illness as equal members of their communities is that they do not see them as capable of contributing to the household or the community. The effects of social determinants such as poverty, conflict, gender disadvantage, social exclusion, etc. on mental illnesses are well known. It is also found that, people are not able to access care due to their social conditions. And due to inadequate treatment, people with mental disorders remain disabled for longer and incur greater health care costs and lesser ability to work, thus worsening poverty.

### **3. Infrastructure and Present Status**

The major changes in mental health scenario began with the asylum fire tragedy at Erwadi, Ramanathapuram district of Tamil Nadu. This disaster opened the eyes of policy makers and the general public to attend to the needs and voices of people with mental illness. . We have come a long way since Independence when no organized care was available. Today mental health issues are seen as part of the public agenda in a few places, partly due to the judiciary's interventions.

While mental health has been stated as part of primary health care system on paper, primary health centers (PHCs) are not equipped to treat people with mental illnesses. Only few PHCs (where programmes such as the District Mental Health Programme or DMHP are implemented) provide mental health care and treatment in the community. In addition, PHCs are not geared towards the provision of chronic disease care (which is a characteristic of most mental disorders), and psychosocial interventions are rarely available in any sector.

#### **3.1 Treatment Facilities**

Most of the district hospitals are not fully equipped and supplied with psychiatric medicines to treat people with mental illness; most often, persons with mental illness are referred to multi specialty centers in the capital cities or big towns. Medical professionals view mental health as an alien subject and do not attach any importance to either learning or practicing it in their day-to-day practice.

There are 42 mental hospitals in the country with the bed availability of 20,893 in the government sector and another 5096 in the private sector hospital settings. This is the current scenario to take care of an estimated 1,02,70,165 people with severe mental illness and 5,12,51,625 people with common mental disorders needing immediate attention.

Psychiatric medicines have been supplied only in a few PHCs, community centers and district hospitals. Amitriptyline, lithium, chlorpromazine (CPZ), phenobarbital, phenytoin sodium, haloperidol, carbamazepine, imipramine and risperidone are made available in a few district hospitals. The commercial rates for risperidone (a drug with lesser known side-effects) are cheaper than CPZ. In spite of this knowledge, the Karnataka State has unfortunately purchased drugs like CPZ in surplus. Adequate laboratory facilities are also lacking in the district hospitals to find out the serum level for lithium administration. None of these drugs are routinely distributed by the government to the primary health centers except in some districts, where DMHP is operational.

In many places Electro convulsive Therapy (ECT "S) continues to be misused/overused and where indicated it is used irrationally, in higher doses & without adequate use of muscle relaxants. The Guidelines drawn up are not adequately circulated; rational use of mental health medicines and technologies is not emphasized. The high costs of medicines for mental health

promotion, & treatment of mental disorders for extended periods of time puts a great strain on the family members and other care givers .

Services like child guidance and rehabilitative services are also available only in mental hospitals and in big cities.

One third of the mental health beds are in the state of Maharashtra and several states do not have mental hospitals. Some mental hospitals have more than 1000 beds and several still have a large proportion of long stay patients. During the past two decades, many hospitals have been reformed through the intervention of the voluntary organizations, media, National Human Rights Commission (NHRC) and the judiciary.

### Availability of psychiatric beds in India

Total psychiatric beds per 10,000 population	0.25
Psychiatric beds in mental hospitals per 10,000 population	0.2
Psychiatric beds in general hospitals per 10,000 population	0.05
Psychiatric beds in other settings per 10,000 population	0.01

A survey of 37 mental hospitals conducted between November 2001 and January 2002 revealed a dismal picture. Apart from poor infrastructure, the greatest deficiencies were in the area of qualified staff. Some mental hospitals do not have even a single psychiatrist on their permanent roster.

### Survey results of mental health facilities in India

Sl. No.	Facilities	Adequate		Inadequate	
		Number	%	Number	%
1	Infrastructure	12	32.4	25	67.6
2	Staff	10	27	27	73
3	Clinical services including investigations	16	43.2	21	56.8
4	Availability of medicines and treatment modalities	28	75.7	9	24.3
5	Quality of food	23	62.2	14	37.8
6	Availability of clothing and linen	15	40.5	22	59.5
7	Recreational facilities	18	48.6	19	51.4
8	Vocational rehabilitation facilities	14	37.8	23	62.2

### 3.2 Mental Health professionals

We have very limited facilities to train human resource in mental health. Ironically, all the existing institutes have become centres to export trained mental health professionals abroad. Many mental health professionals are immigrating to other developed countries, where jobs are

more lucrative. For instance in 2003 ,more than 82 psychiatrist sought short term and long term employment in the United Kingdom during UK’s international recruitment drive.

Undergraduate training in psychiatry has not changed despite many efforts and this continues to be a major barrier to create medical doctors adequately trained in psychiatry after their basic training. Some of the government and private medical colleges do not have the departments of psychiatry in its full strengths to train young medical graduates in psychiatry,

Inadequate mental health human resource is a major barrier in caring for people with mental illness in the community. Most districts do not even have public sector psychiatrists. Very few mental health professionals are based in rural areas. Many states allow public sector psychiatrist to have private clinics.

### **Availability of mental health professionals in India**

Number of psychiatrist per 100, 000 population	0.2
Number of psychiatric nurses per 100,000 population	0.05
Number of psychologist per 100,000 population	0.03

### **3.3 General Hospital Psychiatry**

It is speculated that the birth of general hospital psychiatry in India was due to lack of sufficient funds to open more mental hospitals. These new units needed mobilization of very few resources like a little space in an already functioning hospital and few mental health professionals to manage the people with mental illnesses. What probably started as an economic necessity, has now become a major force in the delivery of health care. A provision for establishment of inpatients wards for people with mental illnesses requiring admission has been provided in the Mental Health Act. It has to be noted that the psychiatric units in the general hospitals are not well established, and are not able able to take care of psychiatric problems associated with other illnesses.

### **3.4 Private Psychiatry**

It is interesting to note that very large numbers of private psychiatrist have located themselves in cities that are district headquarters but are not the state capitals. The reason could be that most state capitals have medical college departments of psychiatry or some other governmental psychiatric facility .A private psychiatric facility would be more welcome in other cities of the state where no such facility exists. The distribution of private psychiatrists in India is in a way related to the position of the states in socioeconomic hierarchy. Thus relatively prosperous states with higher number of literate people (like Kerala and Tamil Nadu) have the highest number of psychiatrists. North zone has proportionately lesser number with the exception of Punjab and Delhi. States of the Central and East zone have the least number of psychiatrists in private practice.

### **3.5 Mental Health Financing**

The country spends 2.05% of the total health budget on mental health(as per the 10<sup>th</sup> 5 year plan). The primary sources of mental health financing in descending order are tax based, out of pocket expenditure by the patient or family, private insurance and social insurance. Government fund for health services are provided both by the states and the center.. The country has a Disability Act, which has included mental illness as the seventh disability. However in reality, people with mental illness rarely avail any benefits available under disability schemes.

### **3.6 Regional Disparity**

The state run health care system in India is striving hard to overcome the regional disparity between rural and urban. The adequate health services and the normal health standards in rural areas seem to be much below the average. Cities and big towns are growing with private health care facilities catering to the needs of middle class and rich communities. The costs for diagnosis and treatment are so exorbitant that some get into debt traps. In rural areas , hardly any facilities exist and the attitude of the government health professionals are often not patient friendly. The budgetary allocation for mental health is very meagre and most of it goes to maintenance of hospitals and a very little portion for treatment.

### **3.7 Non-Governmental Organisations (NGOs)**

NGOs involved with mental health work mainly in the areas of advocacy, promotion, prevention, treatment and rehabilitation. Additionally,they are also involved in counseling, suicide prevention, training of lay counselors, and provision of rehabilitation programmes through day care, sheltered workshops, halfway homes, hostels for recovering patients and long term facilities. There are also self-help groups of parents and people with mental illness that have been recently established. It has to be noted that most of the NGOs have their setups and outlets in the urban areas catering to the needs of middleclass and higher socio- economic groups.

It is evident from the above reading that mental health care in India is characterized by:

- (i) Very limited mental health care facilities;
- (ii) Grossly inadequate professionals to provide mental health care;
- (iii) Less than 10% of the people who require urgent care are getting any care;
- (iv) Families are the current care providers but with limited support and skills for care - giving
- (v) No support schemes for voluntary organization;
- (vi) Lack of a regular mechanism for public mental health education;
- (vii) Limited administrative structure for monitoring the mental health programme and
- (viii) Limited budget for mental health care as part of the total budget

The existence of many mentally challenged persons being taken to Faith healers is because of the absence of mental health facilities. Many of these illnesses are preventable, as well as treatable as they are acute reactions to a situation, only if they are diagnosed in time & handled appropriately, not allowing them to be neglected, so that they progress unchecked into a chronic mental health problem. Helping build a HIGH EMOTIONAL QUOTIENT to deal with ups & downs of life is very important. Contributing to building this in the health as well as education system is important. Recommended reading related to this could be given. Use of simple tools eg Holmes & Rahe Stress index to assess levels of Stress before the fall out presents itself as acute crisis or a serious psychosomatic disease, could be done.

Stress Management approaches have to be adapted to deal with the problem long before the stress manifests as a mental problem. More important is to address roots of stress.

#### **4. Policy and legislation**

##### **4.1 National Mental Health Programme (NMHP) 1982**

The National Mental Health Program is the outcome of various developments in providing mental health care through different methods and to achieve the overall goals of the health care in general. The first concerted efforts to formulate a national program were held in July 1981. Later, in August 1982, a small group of experts met to consider the revised document and finalize the same. This document was presented to the Central Council of health and family welfare and the committee recommended the NMHP for implementation.

The **objectives** of the programme are:

- To ensure availability and accessibility of minimum mental health care for all in the foreseeable future, particularly to the most vulnerable and underprivileged of the population
- To encourage application of mental health knowledge in general health care and social development.
- To promote community participation in mental health services development and to stimulate effort towards self-help in the community.

The specific **approaches** suggested for the implementation of the NMHP are:

- Diffusion of mental health skills to the periphery of the health service system
- Appropriate appointment of tasks in mental health care
- Equitable and balanced territorial distribution of resources
- Integration of basic mental health care with general health services
- Linkage to community

### **4.1.1 Progress of the NMHP**

From the time of the formulation of the NMHP in August 1982, in the last two decades the following initiatives and activities have been taken up in districts where the district mental health programme has been implemented:

- Sensitization and involvement of state level programme officers
- Workshops for voluntary agencies
- Workshops for mental health professionals namely psychologists, psychiatric social workers and psychiatric nurses
- Training programmes in public mental health for programme managers
- State level workshops for the health directorate personnel, development of models of integration of mental health into primary health up to the district level
- Preparation of support materials in the form of manuals, health records for different types of health personnel and health education materials
- Training program for teachers of undergraduate psychiatry
- Initiation of district mental health programme in 28 districts of 22 states
- Expansion of district mental health programme for 100 districts with the budgetary allocation of rupees 190 crores in the 10<sup>th</sup> five-year plan (2002-03 to 2006-07).

### **4.2 The District Mental Health Programme (DMHP)**

The DMHP, which operates as part of the National Mental Health Programme was launched in 1996-97 in four districts. By 2000 the DMHP was extended to 22 districts in 20 States and Union Territories and by 2002, it was further extended to 27 districts in 22 States and Union Territories, providing for services to over 40 million of the population. In the current 10<sup>th</sup> plan period the government has announced the programmes extension to 100 districts across the states, with a total budget outlay of 200 crore rupees

There have been many barriers to achieve the goals set out in the 1982 document. The goals were too ambitious to begin with and sufficient attention was not paid to all aspects of implementation of NMHP. The other important barrier has been the lack of funding. Though NMHP came up in 1982 the subsequent three five years plans did not make adequate funding allocation. Further even the funds allotted were not fully utilized. It was only in the 9<sup>th</sup> Five-year plan that a substantial amount of Rs 28 cores was made available and it was projected to be Rs 190 cores in the 10<sup>th</sup> Five-year plan.

The critical review of District Mental health programme reveals that:

- a. There was lack of administrative clarity to utilize the allocated funds. The programme looked good on paper, but was extremely unrealistic in its targets, especially considering the available resources of manpower and funds for its implementation.
- b. The approach was top down and did not take into consideration the ground realities. The poor functioning of the primary health care in India in general and the low morale of the health workers not taken into account. A structure that was attending to given tasks so inadequately would certainly be unable to absorb new targets of integration.
- c. The DMHP continues to be the extension of professionals rather than integration of mental health with primary care

Central Government has sanctioned DMHP in 100 districts in the year 2004. The districts are yet to implement the programme and to appoint required mental health professionals for the programmes. It is to be noted that a few district hospitals do not have psychiatrists and the facilities to support the mobile team of the DHMP.

#### **4.3 National Health Policy- 2002**

The 2002 National Health Policy (NHP 2002) refers twice to mental health. In its assessment of the current scenario, Section 2.13 states that: *‘Mental health disorders are actually much more prevalent than is apparent on the surface. While such disorders do not contribute significantly to mortality, they have a serious bearing on the quality of life of the affected persons and their families. Sometimes, based on religious faith, mental disorders are treated as spiritual affliction. This has led to the establishment of unlicensed mental institutions as an adjunct to religious institutions where reliance is placed on faith cure. Serious conditions of mental disorder require hospitalisation and treatment under trained supervision. Mental health institutions are woefully deficient in physical infrastructure and trained manpower. NHP 2002 will address itself to these deficiencies in the public health sector’.*

Section 4.13 states the policy prescription towards mental health: *‘NHP 2002 envisages a network of decentralized mental health services for ameliorating the more common categories of disorders. The programme outline for such a disease would involve the diagnosis of common disorders, and the prescription of common therapeutic drugs, by general duty medical staff.*

The proposed National Mental Health Policy outlines the prioritized agenda for extending within a pragmatic time frame basic mental health care facilities to all sections of the populations across the country by the year 2020.

#### **4.4 Legislations Related to Mental Health:**

The Mental Health Act of 1987 and the Persons with Disabilities Act 1995 are the two legislations that are directly applicable to people with mental illness. While these are legislations, the World Mental Health Atlas 2005, reports that there is no Mental Health Policy in India.

##### **4.4.1 The Mental Health Act (MHA), 1987**

Mental Health Act is “*an act to consolidate and amend the law relating to the treatment and care of mentally ill persons, to make better provision with respect to their property and affairs and for matters connected therewith or incidental thereto*”. In the Mental Health Act, 1987, a modest attempt has also been made to bring mental illnesses on par with physical illnesses, thus reducing the stigma attached to mental illnesses

The Mental Health Act is not just a cosmetic improvement over the out dated Indian Lunacy Act 1912, but represents the conclusion of lengthy presentation by the Indian Psychiatric Society to the Government of India. This Act came into force in April 1993, as per the Government of India order, even though it is still in hibernation in some states. The establishment of mental health authorities, both at the center and state is a welcome step. These authorities are expected to act as a friend, philosopher and guide to the mental health services. Provisions have been made for establishing separate hospitals for children under the age of 16 years; for people abusing alcohol and other drugs and for other special groups. Emphasis on outpatient care has been made to safeguard the human rights of the mentally ill person. Stringent punishment has also been prescribed for those who subject the mentally ill to physical and mental indignity within hospitals.

The notion of care in the community has not been addressed in the current legislation. No effort has been made to provide after care services for the discharged patients. There is no thinking over the alternative to hospital care. Authorities are using the clauses of the act leading to many medico-legal problems, and difficulties for the private nursing homes.

**The Ground Realities of its Implementation:** The Mental Health Act has not been implemented in Arunchal Pradesh, Chhattisgarh, Uttaranchal, Bihar, and Orrisa. State Mental health Authority has not been constituted in Arunchal Pradesh, Chhattisgarh, Uttaranchal, Bihar and Orrisa. Mental health rules have been framed only in Goa, Manipur, Sikkim, Assam, Chandigarh, Delhi, Gujarat, Madya Pradesh, Mizoram, and Tamil Nadu.

##### **4.4.2 The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995**

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995, commonly called the PWD act came into force on February 7, 1996. This law is an important landmark and is a significant step in the direction of ensuring equal opportunities for people with disabilities and their full participation in the nation building. The Act provides for

both preventive and promotional aspects of rehabilitation like education, employment and vocational training, job reservation, research and manpower development, creation of barrier-free environment, rehabilitation of persons with disability, unemployment allowance for the disabled, special insurance scheme for the disabled employees and establishment of homes for persons with severe disability etc. There are also statutory bodies for implementing the Act at central and state levels.

Even though it is encouraging that mental illness has been considered in the act, the later chapters of the act do not talk about any provisions to be given or set aside for people with mental illness. The act also does not assure the right to treatment. While there is much talk about the implementation or lack of implementation of the Act, there is little understanding about the indicators to measure the level of implementation. At present, conducting a session on the Act or putting up posters on the Act, are referred to as 'advocacy'. A clearly defined set of indicators for the implementation needs to be worked out. There is also a great need to come up with strategies to decentralize the implementation of the Act at the district/ taluk and village level.

## **5. Conclusion**

The rate of mental illness is being increasingly recognised across different divides like the rich and the poor, urban and rural and so on. With some help from the judiciary, it seems like the states are taking note of the gravity of the issue and attempting to address the needs of people with mental illness.

Health including mental health is a fundamental right. Millions in India perhaps, don't know that it is their right to avail treatment. People with mental illness are crying '*My name is today*'' Do we hear their voice?

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