



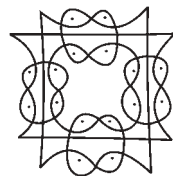
Strengthening ESC Rights  
Activism in India

# Advancing Right to Health: The Indian Context

Sama – Resource Group for Women and Health

BEYOND THE CIRCLE

# Advancing Right to Health: The Indian Context



*Sama*

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Resource Group for Women and Health

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# Preface

The paper on *Advancing Right to Health: The Indian Context* is published on behalf of the Beyond the Circle Project which brings together a small number of academics and representatives of NGOs with the aim to advance the enjoyment of economic, social and cultural rights in India. In particular, the initiative aims to contribute to clarifying the idea of rights based approach to ESC issues including capacity building to advance these set of rights. An essential element of advancing ESC rights is acquiring clarity on the scope and content of specific rights such as right to health, education, housing, food etc. In fact, the vague nature of these sets of rights poses a challenge as well as an obstacle to advancing them. One way is to articulate these rights based on the national and international standards. For example, what does the Indian Constitution say about right to education or housing or how the Indian courts have interpreted the Constitution to define these rights? The International Covenant on Economic, Social and Cultural Rights (ICESCR) is another source for deriving the meaning of these rights. The Committee established under the ICESCR has issued a number of very important General Comments related to specific rights. Similarly, the meaning of these rights could also be derived from other international standards such as the International Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child.

Understanding the national and international standards is the first step and the next step is to define the rights based on the national and local context. For example, what is the meaning of access to food or health in the Indian context. Beyond the Circle Project as part of its efforts to capacity building decided to develop framework documents on specific rights to contribute to further clarifying the meaning of ESC rights. In the first phase it selected the right to food, health, housing and education to clarify the meaning of these rights.

This paper on *Advancing Right to Health: The Indian Context* was written by Sama-Resource Group for Women and Health.

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This and other papers in this series were produced with the aim of strengthening further learning as well as to contribute to discussion and debate on the meaning of ESC rights. We therefore would appreciate comments and feedback on this and other papers produced in this series. We also hope that through these papers Beyond the Circle would make a contribution to advancing economic, social and cultural rights in India.

**Narayan Banerjee**

Convener- Beyond the Circle Project

# Introduction

One of the primary responsibilities of the State is to provide health services to all its citizens. On paper, India has a reasonably well-formulated healthcare structure that has the potential to reach out to a large section of the population. However, despite this elaborate structure and the advancement of medical sciences, the reality shows a dismal picture. The percentage of population actually covered by the public health services is reported to be a mere 30 percent. About five lakh people died of Tuberculosis (TB) in 2000 and this number is almost unchanged since independence.<sup>1</sup> In India 47 percent children under three years of age are undernourished by weight,<sup>2</sup> as compared to only 6 percent in Brazil.<sup>3</sup> Children below 3 years of age among the Scheduled Castes are twice as likely to be undernourished than children in other groups. Around six lakh children die each year from an ordinary illness like diarrhoea.<sup>4</sup> Preventable diseases like malaria and tuberculosis are on the rise despite specific government programmes to control them. The outbreak of dengue in India in 1996-97 saw 16,517 cases and claimed 545 lives.<sup>5</sup> Numerous studies and statistics point towards a situation that is worsening day by day.

The two National Family Health Surveys (NFHS), carried out in 1993 and in 1998, found that maternal mortality was not only high, but progressively increasing (437 and 540 respectively). Moreover, complications during pregnancy are greater for adolescents (under age 16) and older women (over age 40). In both the surveys, the rural MMR (Maternal Mortality Rate) was much higher than urban MMR (434 compared with 385 in NFHS-1 and 619 compared with 267 in NFHS-2). However, a majority of maternal deaths are preventable given that both knowledge and means of prevention are available.

The problems that a common citizen faces in accessing healthcare are not uniform. They vary due to a number of factors: physical location, economic strata, gender, caste, available facilities, affordability of the available services, etc. While the urban areas overflow with health facilities for those with paying capacity - trained doctors, nurses, ultra-modern diagnostic centres, hospitals-both public and private - all these seem to disappear as one moves even 50 kilometres into the rural areas.

On an average, one hospital bed caters to 300 patients in urban areas. This includes beds at private facilities. In comparison, rural areas have 8 times less beds as per the required norm of one bed per 500 persons.<sup>6</sup> The ratio of hospital beds to population in rural areas is fifteen times lower than that for

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1 TB India 2003, RNTCP Status Report, Central TB Division, DDHS, GOI.

2 NFHS II, 1998.

3 *Whatever Happened to Health For All by 2000 AD, Towards the People's Health Assembly*, Book 2, 2000.

4 Policy Brief, CEHAT and JSA, 2004.

5 Misra, Chatterjee, Rao. *India Health Report*. Oxford University Press, New Delhi, 2003.

6 *Operationalising Right to Healthcare in India*, Ravi Duggal, CEHAT.

urban areas.<sup>7</sup> Accessibility is poor and people have to walk miles to get to a PHC. In many rural areas, the poorer families often cannot take the sick to the hospital, leave alone diagnose or treat them. Even where facilities exist, they are plagued with a chronic lack of trained doctors, medical support staff, drugs, equipment and essential supplies necessary for diagnosis and treatment. The ratio of doctors to population in rural areas is almost six times lower than the availability of doctors for the urban population.<sup>8</sup>

There is also a considerable disparity between those who can pay for services and those who cannot. The proportion of people who could not seek healthcare due to lack of money increased significantly between 1986 and 1995, from 10 percent to 21 percent in urban areas and 15 percent to 24 percent in rural areas.<sup>9</sup> In India 40 percent of those who are hospitalised are forced to borrow money or sell assets to cover expenses.<sup>10</sup> Over 2 crores of Indians are pushed below the poverty line every year because of out of pocket spending on healthcare.<sup>11</sup> Only 20 percent of the population can access all the essential drugs that they require.<sup>12</sup>

According to the latest NFHS data (IIPS 2002), infant mortality rate (IMR) among the poorest 20 percent of the population is 109, which is 2.5 times the IMR among the top 20 percent population of the country. Under-five mortality among the poorest 20 percent of the population is 2.8 times that of the richest 20 percent. Child mortality (1-5 yrs age) among children from the 'Low standard of living index' group is 3.9 times that from the 'High standard of living index' group. Despite having a better health status overall, the richest 20 percent of the population, is six times more likely to access hospitalisation than the poorest 20 percent. Further, a mother from the richest 20 percent of the population is 3.6 times more likely to receive antenatal care from a medically trained person than a poor mother.<sup>13</sup> This inequity is reflected also in the health outcomes. According to the NFHS 1998 data, infant and child mortality, malnutrition among women and children, prevalence of communicable diseases like tuberculosis and malaria, unattended childbirth are between 2 to 4 times higher in the poorest sections of the society.

The poor access of marginal groups to health services adds another dimension to the inequity in access. Data from NSS 1996 shows that the Scheduled Tribes had 12 times less access in rural areas and 27 times less in urban areas as compared to others. For the Scheduled Castes, the disparity was 4 and 9 times in rural and urban areas respectively. The NFHS 1998 figures reveal that the health

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7 Central Bureau of Health Intelligence, Directorate General of Health Services, Ministry of Health and Family Welfare. Health information of India, 2000 & 2001.

8 Ibid.

9 National Sample Survey Organisation, Department of Statistics, GOI, 42nd and 52nd Round.

10 Ibid.

11 Mahal A. [www.worldbank.org](http://www.worldbank.org)

12 National Coordination Committee for Jana Swasthya Sabha, Health For All Now, 2004.

13 *The Right to Healthcare - Moving from Idea to Reality*, Abhay Shukla, 2001.

outcomes of these groups are worse in urban areas (1.5 times lower than the other groups) in spite of the relatively better overall physical access in urban areas.

Even though the World Health Organisation has set the standard for expenditure on public health at 5 percent of the GDP, the Indian government spends only 0.9 percent of its GDP on healthcare. The structural adjustments and economic reforms of the nineties have further added to this decline with an overarching push towards reduction of public investment in healthcare, thereby encouraging the private sector to take over health services. Such a move only ensures that the poor will continue to be denied access to healthcare services, since profit, and not social commitment, is the driving force of the private enterprises that would provide such fundamental facilities and services.

Health, however, is not about disease, doctors and drugs alone. Good health is dependent on many other socio-economic conditions, basic amenities available to the people and their working and living conditions. On many occasions, environmental or cultural factors also play an important role in determining the health condition of an individual or community. Along with providing health facilities and services, the State is also required to take care of all such underlying determinants of health. However, even a cursory glance into these underlying factors presents a dismal picture.

According to the NFHS 1998 data, piped water, a basic necessity, is available to only 25 percent of the rural population and 75 percent of the urban population. Moreover, half the urban population and three-fourths of the rural population does not purify/filter water in any way. Flush and pit toilets, key elements of sanitation, are available to only 19 percent of the rural population and 81 percent of those living in towns and cities, whereas 73 percent of those in rural areas use wood as cooking fuel, 48 percent of urban households use LPG and biogas, compared to 6 percent rural households. Forty-one percent of rural houses are kachha, as against 9 percent of urban houses. There are numerous studies that indicate the abysmally poor environmental health in both rural and urban locations as well as unhealthy and unsafe working conditions in most work situations, including many organised sector units that are governed by various social security provisions.<sup>14</sup>

Policies of the last fifty years have clearly failed to provide healthcare to a bulk of India's population, something that the Indian State has been committed to constitutionally, by way of the Principles of State Policy directive. The situation has reached a stage where any minor reforms in the current approach are of little significance, unless health is viewed as a fundamental right that can be enforced and claimed by the people. This document attempts to examine the prevailing conditions and issues in that light, and tries to articulate a framework to work towards operationalising the Right to Health as a basic, fundamental right.

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14 *Operationalising Right to Healthcare in India*, Ravi Duggal, CEHAT.

## Chapter I

# What is Right to Health

*“Health is one of the goods of life to which man has a right; wherever this concept prevails the logical sequence is to make all measures for the protection and restoration of health to all, free of charge; medicine, like education, is then no longer a trade - it becomes a public function of the State.”*<sup>15</sup>

The Preamble of the World Health Organisation’s constitution states “Health is a state of complete physical, mental, social well-being, and not merely the absence of disease or infirmity.” This positive and broad definition of health is the bedrock on which the claim of the Right to Health as a fundamental right can be established. This definition helps to capture the notion that health is quintessentially relative, “depending on individual and medical perceptions of what is ‘normal’ or ‘habitual’.” Medical sociologists have observed that individual perceptions of health and illness not only depend on personal, physical or psychological attributes, but on cultural expectations as well. Thus, the Western biomedical concept of health as a pure correlation between disease and medicine should be propagated with caution when it comes to a diverse country like India.

To give space to the diverse worldview that exist in the Indian context, the present attempt is not to arrive at a universal definition of health, but to focus on the:

1. Objective criteria like health status of the society by relying on a series of indicators with special emphasis on health status of vulnerable groups.
2. The understanding of the specific configuration of traditional culture and subjective understanding of the community’s need and its notion of well-being and illness.

### **The formulation of Right to Health**

We are no doubt in an inimical era of global capital that on the one hand wants to make profit out of anything it lays its hands on and on the other propagates the concept of ‘limited welfare-ism.’ However, we are also a part of a world where social and economic rights are increasingly at the forefront and an important cause for advocacy. Modern human rights are a civilisation’s achievement; a historic effort to identify and agree upon what governments should not do to people and what they should ensure to all. Human rights are non-provable statements that derive their legitimacy from having been developed, voted upon and adopted by the nations of the world. They achieve their status from being incorporated into the domain of international law and not from divine inspiration or religion.

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15 Henry Sigerist, Preamble.

The goal of linking health and human rights is to contribute to advancing human well-being beyond what could be achieved through an isolated public health or human rights-based approach. This is because human rights are rights of individuals that are inherent by virtue of being human and apply to all people around the world. It principally involves the relationship between the state and the individual. However, we must not forget that Human Rights law is philosophically founded on a “theory of natural law springing from the Western traditional belief of a higher universal, permanent, or divine order of nature.”<sup>16</sup> This poses a logical enigma to the human right to health. As natural rights originate from nature and nature itself prevents the attainment of health, it becomes clear that humans cannot have a natural right to health. A true natural right to health would logically extend to eternal life in a perpetual state of well-being. This is unachievable and hence there is a reluctance to view ‘health’ as a legal human right.<sup>17</sup>

This conceptual difficulty in formulating a truly enforceable legal right to health should be combated by laying down a precise and crisp definition of the concept of ‘right to health’ and correspondingly, clarifying the nature of duties and responsibilities both of the state and individuals. To assert that individuals too have a duty has a double connotation - it means individuals have a duty to preserve their health and a commitment not to jeopardise the health of other individuals. However, often this assertion is taken to mean that an individual’s action has a profound effect on health, irrespective of whether the State meets its duty or not. This is problematic. This is because it has the potential to put the blame of ill-health entirely on the citizens living in discomfort and distress. Thus, an individual’s responsibility towards one’s health and towards the health of others is not the end of a treatise on right to health, but should be duly complemented by the duty of the State towards the health of its people.

In this situation, it is important to explore the connection between health and human rights. We can delineate three relationships, each of which focuses on an important aspect of this critical linkage.

The first relationship, which can be diagrammed as  $H \rightarrow HR$  concerns the potential impacts of health policies, programmes, and practices on human rights. Recognition of the complementarity of public health goals and human rights norms can lead to more effective health policies and programmes.

The second relationship, which can be diagrammed as  $H \leftarrow HR$ , explains that violations or lack of fulfilment of any and all human rights have negative effects on physical, mental, and social well-being, in other words, health.

The third relationship, which can be diagrammed as  $H \leftrightarrow HR$ , conveys the idea of an inextricable connection. The central idea of the health and human rights movement is that both of these act in synergy. Promoting and protecting health requires concrete efforts to promote and protect human

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16 *The Right to Healthcare in the Americas - A Comparative Constitutional Study* edited by Hernan L. Fuenzadilla-Puelma/ Susan Scholle Connor, Pan American Health Organisation USA.

17 Ibid.

rights and dignity, and greater fulfilment of human rights necessitates better attention to health and to its social determinants.

The interface between health and human rights has rarely been researched. With few exceptions, notably involving access to Healthcare, discussions about health have not included human rights considerations. Yet health and human rights are both powerful, modern approaches to defining and advancing human well-being. However, meaningful dialogue about interactions between health and human rights requires a common ground. Thereby, our attempt is to work out a mutually accessible framework in order to explore the potential for health to be seen as a human rights issue.

## **A Provisional Framework: Linkages between Health and Human Rights**

### ***1. The Impact of Health Policies, Programmes and Practices on Human Rights***

Healthcare is provided through many diverse public and private mechanisms. The responsibilities of public health are carried out through policies and programmes promulgated, implemented, and enforced by, or with, support from the state. Therefore, the first linkage may be best explored by considering the impact of public health policies, programmes, and practices on human rights. The three central functions of public health are: assessing health needs and problems; developing policies that address priority health issues; and assuring programmes to implement strategic health goals. Potential benefits and burdens on human rights may occur in the pursuit of each of these major areas of public health responsibility.

For example, assessment involves collection of data on health problems in a population. But data is not collected on all possible health problems. Thus, a state's failure to recognise or acknowledge health problems that preferentially affect a marginalised group may violate the right to non-discrimination by leading to neglect of essential services, and as a consequence, may adversely affect the realisation of other rights, including the right to "security in the event of sickness or disability" or to the "special care and assistance" to which mothers and children are entitled (Universal Declaration of Human Rights, Article 25).

The methodology of data collection may also create additional human rights burdens. For instance, personal health status or health behaviour information (such as sexual orientation or history of drug use) has the potential for misuse by the state, whether directly or if it is made available to others, resulting in grievous harm to individuals and violations of many rights. Thus, misuse of information about HIV infection status has led to -

- Restrictions on the right to work and to education.
- Violations of the right to marry and have a family.
- Attacks upon honour and reputation.

- Limitations of freedom of movement.
- Arbitrary detention or exile.
- Cruel, inhuman, or degrading treatment.
- Denial of healthcare.

The second major task of public health is to develop policies to prevent and control priority health problems. For example, if a government refuses to disclose the scientific basis of health policy or permit debate on its merits, or refuses to inform and involve the public in policy development, the rights to “seek, receive and impart information and ideas ... regardless of “frontiers” (UDHR, Article 19) and to take part in the government directly or through freely chosen representatives” (UDHR, Article 21) may be violated. Then, prioritisation of health issues may result in discrimination against individuals, as when the major health problems of a population defined on the basis of sex, race, religion, or language are systematically given lower priority.

The third core function of public health, which is to ensure services capable of realising policy goals, is also closely linked with the right to non-discrimination. When health and social services do not take logistic, financial, and socio-cultural barriers to their access and enjoyment into account, intentional or unintentional discrimination may occur. For example, maternal and child health services should take into account details such as hours of service, accessibility via public transportation and availability of day-care that may strongly and adversely influence service utilisation.

It is essential to recognise that in seeking to fulfil each of its core functions and responsibilities, public health may burden human rights. In fact, public health has a long tradition, anchored in the history of infectious disease control, of limiting the “rights of the few” for the “good of the many.” Consequently, coercive measures such as mandatory testing and treatment, quarantine and isolation are considered basic measures of traditional communicable disease control. However, it is important to note that public health, as a state function, is obligated to respect human rights and dignity. The often-perceived conflict between the human rights approach and the public health approach, between individual good and societal good is superficial and one does not generally exclude the other. A deeper look reveals that since the rights of individuals are interdependent and interlinked neither can exist without the other. Eventually, all and any human rights infringement affects all of us and all systems of a society if it aims to be equitable.

The principle that certain rights must be restricted in order to protect the community is explicitly recognised in the International Bill of Human Rights: limitations are considered permissible to “(secure) due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society” (UDHR, Article 29). However, the permissible restriction of rights is bound in several ways. First, certain

rights (e.g., right to life, right to be free from torture) are considered inviolable under any circumstances. Restriction of other rights must be:

- In the interest of a legitimate objective.
- Determined by law.
- Imposed in the least intrusive means possible.
- Not imposed arbitrarily.
- Strictly necessary in a “democratic society” to achieve its purposes.

## ***II. Health Impacts Resulting from Violations of Human Rights***

Health impacts are inherent in the popular understanding of certain severe human rights violations, such as torture, imprisonment under inhumane conditions, and “disappearances.” However, health impacts of rights violations go beyond these issues in at least two ways:

1. The duration and extent of health impacts resulting from severe abuses of rights and dignity remain generally under appreciated. Torture, imprisonment under inhuman conditions, rape, or mistreatment lead to severe, probably lifelong effects on physical, mental, and social well-being.
2. Violations of most, if not all human rights have negative effects on health. For example, the right to information may be violated when cigarettes are marketed without governmental assurance that information regarding the harmful effects of tobacco smoking will also be available. Other violations of the right to information, with substantial health impacts, include governmental withholding of valid scientific health information about contraception or measures (e.g. condoms) to prevent infection by a fatal virus (HIV).

## ***III. Health and Human Rights---Exploring an Inextricable Linkage***

Promoting and protecting human rights is inextricably linked to the challenge of promoting and protecting health, which derives in part from recognition that health and human rights are complementary approaches to the central problem of defining and advancing human well-being. This fundamental connection leads beyond the single, albeit broad mention of health in the UDHR (Article 25) and the specific health-related responsibilities of states listed in Article 12 of the ICESCR, including:

- Reducing stillbirth.
- Reducing infant mortality.
- Promoting healthy child development.
- Improving environmental and industrial hygiene.

- Preventing, treating, and controlling epidemic, endemic, occupational and other diseases.
- Assuring medical care.

Therefore, exploration of the intersection of health and human rights may help revitalise the health field as well as contribute to broadening human rights thinking and practice. The health and human rights perspective makes efforts to provide us new avenues for understanding and advancing human well-being in the modern world.

However, at the outset it is also important to put forward the limitations that a human rights framework poses. Researching the history of human rights discourse, it becomes quite clear that human rights work is often ad-hoc, driven by the politics of violation and sectionalised by the simplistic application of the UN's categorisation of rights issues by such factors as race, sex, age and nationality. Because of this situation, human rights norms have tended to be applied in ways that reflect the claims of specifically situated groups or individuals. This divide has led to the lack of a proper understanding on what rights mean for individuals coming from different ethnic, class, religious, political and economic backgrounds. Moreover, resources being limited, priorities have to be set according to the most urgent needs of the most number of people without disrupting the basic tenets of the human rights framework. As human rights framework is grounded on the premise of equality of all human beings, acts of omission and acts of commission are important in the entire discourse of actualising human rights - because even choosing what to actualise is a political activity. In that sense, all human beings not being equal, clearly, working on human rights does involve taking sides and is necessarily political.

Thus, in order to achieve the most comprehensive and effective framework, the right to health must be spelled out concretely in terms of availability, accessibility, acceptability, and quality, taking into consideration the specific needs of the people. As such, the right to health or healthcare<sup>18</sup> or health protection<sup>19</sup> should encompass a State's duty to provide both healthcare and healthy conditions, irrespective of gender, class, race, religion, sexual orientation, or other status. The right to health in our understanding includes the fulfilment of all the following criteria and conditions:

#### 1. Healthcare

- Right to healthcare facilities - hospitals, laboratories, surgical and diagnostic facilities with adequate physical infrastructure, skilled human-power and basic medication.
- Access to quality care and treatment - competent, rational and gender sensitive.
- Ability to exercise choice in utilisation of health services.

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18 *The Right to Healthcare - Moving from Idea to Reality* by Abhay Shukla, CEHAT 2001.

19 *The Right to Healthcare in the Americas - A Comparative Constitutional Study* edited by Hernan L. Fuenzadilla-Puelma/ Susan Scholle Connor, Pan American Health Organisation USA.

- Access to preventive attention and treatment, e.g. vaccination, preventive measures for epidemics or other emergencies.
- Access to information and patient -friendly grievance redressal mechanisms.

## 2. Health Determinants

- Access to safe drinking water and sanitation.
- Adequate standard of living and adequate housing.
- Equitable distribution of food.
- Availability of safe and healthy workplace and healthy environment.
- Assurance for having education and information relating to health
- Freedom from discrimination and discriminatory practices on the basis of gender, caste, sexual orientation and religion.
- Freedom from violence at all levels - family, community and state.
- Access to minimum wages for the organised as well as unorganised sectors.

It is in such an understanding of the right to health framework that we envision that the age old proverb “health is wealth” will not remain a fancy idea confined to our thoughts, but can become a concrete reality. For long, people all over the world have ranked health as one of the greatest needs, but when it comes to decision-making and setting priorities, health tends to take a back seat. This can only be reversed once we begin to discard the notion that health problems are individual tragedies, and attempt to look beyond and challenge the political, economic and social environments that generate and sustain them. This is feasible if we begin to believe in the right to health as an entitlement and not a privilege or favour.

## Chapter 2

# Issues under Right to Health

The signatories of the Declaration of the Alma Ata representing nearly all governments of the world<sup>20</sup> made an international commitment to achieve ‘Health for All’ by the year 2000. The Alma Ata Declaration upheld that health is a fundamental human right and that gross inequalities in health status are intolerable. “An acceptable level of health of all people of the world by the year 2000 can be attained through fuller and better use of the world’s resources, a considerable part of which is now spent on armament and military conflicts.”<sup>21</sup>

The goal of ‘Health for All’ was founded on two basic arguments: *The provision of healthcare is the state’s obligation towards its citizens. Primary Health Care through community based health workers is strategically possible.*<sup>22</sup>

Primary Health Care (PHC), with its vision to ensure Health for All, was a revolutionary departure from status quo. It recognised that without social justice, Health for All could never be achieved. It offered a social analysis of health, explaining that the causes of poor health were not diseases alone, but a combination of prevailing socio-economic conditions, political structures and ideologies, as well as environment.<sup>23</sup>

However, though PHC correctly recognised health as an indicator of people’s lives, it could not achieve the desired result in the last 25 years. This is because, to ensure Health for All, complimentary political change is necessary and essential. To actualise what PHC envisioned, it was necessary to prepare a backstage in which political actors and parties would act in favour of marginalised groups within the country and throughout the world. Unfortunately, the last two decades have witnessed the concurrent rise of imperialist forces, globalisation and privatisation, which are antithetical to the interests of marginalised sections.

### Right to Health in the age of Globalisation

Globalisation, as practiced today, is inherent with contradictions of what it originally promised to perpetuate. It can be broadly characterised by four often conflicting and interdependent themes,<sup>24</sup> which in turn pose major constraints, particularly for the attainment of health:

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20 International Conference on Primary Health Care, sponsored by WHO and UNICEF, held in Kazakhstan 1978.

21 Alma Ata Declaration 1978, quoted in *A Call for Action - Governments Take Responsibility for Women's Health, Primary Health Care and Women's Reproductive and Sexual Rights*, WGNRR, pg. 4.

22 Ibid. pg. 7.

23 Ibid. pg. 4.

24 Ibid. pg. 13.

1. **Economic transformation:** The world economy has grown enormously. The average value of any foreign exchange transaction has risen sharply. Reducing government regulation of everything that could diminish profits is leading to financial volatility and is creating unemployment, hardship, labour-insecurity and marginalisation since the unorganised private sectors do not provide job guarantees nor do they maintain minimum wages. This economic expansion and liberalisation has resulted in greater inequality both within and between countries, which is then reflected in the health sector.
2. **New trade regimes:** The unelected and unrepresentative bodies - World Trade Organisation (WTO), International Monetary Fund (IMF), World Bank - are widely propagating and favouring transnational corporate interests and private capital rather than people, and are deciding upon global, national, economic and social policies.<sup>25</sup> These macroeconomic policies and in particular unfair means of trade, unrealisable debt and continued appropriation of national resources (human and material) are imposed on developing countries. As a result, in the eighties, Third World was the net exporter of money through debt payment. This is much greater than the total inflow of money through loans, bilateral, multilateral aid and Foreign Direct Investment (FDI).<sup>26</sup> This one way flow of money and resources has its root in the Structural Adjustment Programmes (SAPs) that were implemented as a process of “economic policy reforms”<sup>27</sup> in poor countries of Latin America, Africa and Asia. Designed by the World Bank and IMF, SAPs were implemented by debtor countries in order to qualify for debt relief as well as to attract foreign investment.
3. **New partnerships in governance:** The entry of the corporate sector in almost all sectors, which were initially managed by government, has profoundly altered the nature of the country’s economy and has ripple effects on the entire lifestyle of people. This included banks, key industries, railroads, toll highways, electricity, schools, hospitals and even fresh water.<sup>28</sup> Until the late 1970s, there had been very insignificant collaboration between private and public sectors, and relationships were often jarring and antagonistic. Today, however, there is a huge convergence and a great deal of discussion about partnerships between the private and public sectors, both at the national and at the global levels. WHO, for instance, is no longer the sole decider about health at the international level but the corporate sector plays a rather manipulating role along with the “new philanthropists” like Bill Gates and Ted Turner, who pledged \$6 billion for vaccines (WHO’s annual budget is less than U\$1 billion).<sup>29</sup> This reinforces the already existing multi-tiered health system, encouraging the movement of

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25 Francais, *Realisation of the Right to Health*, Human Rights Commission 2003.

26 Amit Sen Gupta, *Health in the Age of Globalisation*.

27 Reading Materials, JSA, Structural Adjustment Programmes, pg. 62.

28 Reading Materials, JSA, What is Neo-Liberalism- A brief definition for activists. pg. 62.

29 Gill Watt, *Globalisation and Health*, Advocacy Internet issue #5, pg. 15.

health professionals from the public sector, inequitable access to healthcare and undermining of the national health systems.

4. **The electronic revolution:** Electronic communication had potential to unite the world and create inflow of information irrespective of time and space. However, to take advantage of this opportunity people need to have access to regular electricity, computers, training and above all, basic education.

### Impact of globalisation on the health of people in India

Once Primary Health Care (PHC) was seen as the medium through which 'Health for All' was to be achieved. However, with the global power coming to the fore, the thrust on PHC by the Alma Ata Declaration has taken a backseat. Policy measures promoting "free" enterprise, deregulation and privatisation have led to decrease in benefits. This has resulted in reduction in expenditure for social services and in eliminating the concept of "public good" or "community."<sup>30</sup> Thus, by reducing the safety net for the poor, it has pressurised the poorest people in the society to find solutions for their lack of education, health, and social security all by themselves.

Health allocations have seen severe cuts, both at the central and state levels, leading to gradual dismantling of the public health services. User-fee is being introduced, which is making the services inaccessible to the chunk of the population of the Third World countries living under the poverty line. The National Health Policy proposes to introduce user fees in public hospitals, couched in the usual sugar-coating of it being

#### The resultant policy measures that followed in India because of SAP were:

- Devaluing of the national currency: the Indian Rupee was first devalued on July 1, 1991 by 10 percent; just after two days there was another 10 percent devaluation.<sup>31</sup>
- Reducing government spending and increasing taxes in order to balance the budget (especially indirect taxes).
- Raising interest rate and decreasing the availability of credit.
- Lowering of tariffs, liberalising i.e. dismantling trade, and investment regulation.
- Privatising public enterprises and selling these to domestic and foreign investors: the share of private sector in the paid-up capital (PUC) of India's corporate sector rose from 27.16 percent at the end of 1990-91 to 56-79 percent in 1996-97.<sup>32</sup>
- Reducing real wages with concomitant rise in the prices of essential goods: price of essential commodities increased between 93 percent and 170 percent during 1991 and 1997. Whether vegetables, fruits, edible oil, cereal or milk products, all have witnessed unparalleled rise in prices, literally transforming even bare necessities into luxuries. Ironically, the increase in prices of luxury items during the same period remained between 2 percent and 70 percent.<sup>33</sup>
- Shifting agricultural and industrial production from staple foods for domestic use and basic goods for domestic use, to commodities for export.

30 Reading Materials, JSA, What is Neo-Liberalism"- A brief definition for activists. pg. 62.

31 Ibid. Also mentioned in Amit Sen Gupta, *Health in the Age of Globalisation*.

32 Ibid.

33 Ibid.

introduced for those who can pay. Global experience of user fees at any level shows that they serve only one purpose - to drive out the poor and the indigent and introduce an inherent hierarchy between those who pay and those who do not. At the conceptual level, this may sound fine as those who can pay should pay, so that those who cannot pay would share the benefits. However, at the ground level, this strategy only accounts for the retraction of the state and the unconstitutional partnership between the public and private organisations, and privately managed care services. In fact, the government hospitals are contracting private sector companies for tasks that were once the prerogative of the government, such as providing daily meals, hygiene and cleaning.

The per capita public health expenditure in India is Rs. 220 (including state and central government expenditures), out of which Rs. 52 to Rs. 60 is spent on rural healthcare. It is evident that there is tremendous dependence of people on private services. Studies have shown that almost 82 percent of healthcare is accessed from the private sector, and most of this makes severe dents on family budgets of the poorer groups, pushing them into indebtedness. Out of pocket expenditure on healthcare is estimated to be almost Rs. 800 to Rs. 900 per capita. According to NSS data, availing medical treatment is the second highest cause of rural indebtedness. In the euphoria of privatisation, with more and more state governments introducing user fees for public health services, this deprivation can only multiply in geometric proportions. The wider determinants of health status are also totally ignored. Water supply, sanitation, transport, communication, environment, and even health education are put outside the confines of the health sector. The focus on the marginalised, that used to be the central focus of the public health system, has shifted completely. Even if it exists on paper, it is never implemented and executed. Thus, both at the level of infrastructure and quality of care, there exists only a 'skeletal structure of services, incapable of contributing in any meaningful manner to amelioration of ill-health.'<sup>34</sup>

In this scenario, international financial agencies have stepped in with loans and grants that are full of peripheral conditions, along with their financial conditions that are extremely brutal and almost unachievable. For example, the World Bank seeks to influence the health policy of India by:

- (a) Virtue of being the largest lender to the sector, even though there is enough evidence that this forms a small part of the entire country's budget.
- (b) Various conditionalities that overrule local expertise and project formulation.
- (c) Thrusting ideas from other western countries with radically different social, cultural, political, economic, ecological and epidemiological contexts.

The World Bank aided projects have not only abandoned the Primary Health Care mandate, but have

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34 Amit Sen Gupta, *Health in the Age of Globalisation*.

arduously contorted the Primary Health Care agenda. The focus has shifted to:

- Selective, cost effective treatment schedules, rather than implementing empowering healthcare processes.
- Secondary hospitals rather than primary healthcare.
- Quantity care rather than quality care.
- Top-down management systems and technology; no initiative to incorporate people and community.
- Development of registered societies as self-sufficient bodies rather than making them accountable to people whom they cater to.

#### **A Government of Andhra Pradesh abstract states:**

1. Resource Mobilisation

- (i) The Development society (including Medical colleges/ Hospitals/ Health Institutions) may raise resource as follows
- (a) Donation in cash or kind from individuals, and philanthropic organisation or central sector undertakings or companies etc.
  - (b) Collection of user charges for service provided including laboratory, diagnostics, etc. Except for nominal registration fees the individuals belonging to below poverty line / while cardholders shall be provided free treatment. ...
  - (c) Charges towards provision of paying rooms, wards.

2. Levy of user charge

The Levy of user charges for various services/ facilities shall be decided by the Director General of Medical and Health services through meeting convened once every year or as and when required or requested for by any members. The user charge shall be reviewed every year or as and when required...

3. Other Powers ...

Hospitals/ Institutions Development Society is also empowered to select contractor for supply of good diet in the institution by calling for tenders or as prescribed by the Government. Development Society / concerned staffs should monitor and ensure the supply of good quality diet to patients as per norms and procedure prescribed by the government from time to time.

*Source: Health, Medical and Family Welfare (MI) Department, G.O. M.S No. 90*

In the last few decades, there has been an increase in fluid investment across borders and opening of ultra-modern, state of the art private clinics through foreign investment. Through all this, the poor and marginalised are losing out further, because of the hefty user-fees that such establishments demand.

The National Health Policy (NHP) also talks about using Indian health facilities to attract patients from other countries. NHP also suggests that such incomes can be termed “deemed export” and should be exempt from taxes. This formulation draws from recommendations that the industry has been

making and specifically from the “Policy Framework for Reforms in Healthcare”, drafted by the Prime Minister’s Advisory Council on Trade and Industry, and headed by Mukesh Ambani and Kumaramangalam Birla. Such a proposal, termed by many as “health tourism”, will divert our best resources to serve the interests of the global health market and create islands of brain and resource drain within the country. The use of domestic facilities for treating patients from outside the country may be encouraged only if such use is restricted to less than 10 percent of the facilities of any institution. It talks of encouraging “the setting up of private insurance instruments for increasing the scope of the coverage of the secondary and tertiary sector under private health insurance packages.” Further, there are repeated references in the policy about “valuable” contributions made by the private sector and the need to “encourage” more such contributions. While the policy is repeatedly critical of the public health system (justifiably so) there is no criticism of the ills of the unregulated private medical care system, though reference is made to the need to develop regulatory norms.

The prices of drugs are also increasing under the umbrella of globalisation and there is a concomitant reversal process, which will take away the self-reliance of the Indian Pharmaceutical Industry, which it achieved almost three decades ago in 1970 with the Indian Patent Act.<sup>36</sup> In fact, with the Indian Patent Act in 1970 and the development of public sector drug companies, the prices of drugs came down with as many as 387 drugs being under the Drug Prices Control Order (DPCO). However, the signing of the WTO Agreement has changed the entire story. Quite obviously, now with globalisation, only 63 drugs are under DPCO<sup>37</sup> and there is no

There is a proliferation of brand names with over 70,000 brands marketed in India, but the 2002 Drug Policy recommends that only 25 drugs be kept under Drug Price Control. As a result, many drugs are being sold at 200 to 500 percent profit margin, and essential drugs have become unaffordable for the majority of the Indian population.<sup>35</sup>

rationalisation of Essential Drugs. With the imposition of excise duty on generic drugs and increased import of essential vaccines, there has been an exorbitant rise in the prices of essential drugs. The price of an anti-TB drug has doubled in a year, which is forcing the poorest of the poor to buy drugs at dollar value. TRIPS (Trade Related Intellectual Property Rights) further helped to speed up this process, as it sanctified monopoly rent incomes by pharmaceutical MNCs. Thus, the thrust of the MNCs is in research and patenting of “life style” drugs that are consumed by people from higher economic classes, rather than on “orphan drugs,” which are the cure for life threatening diseases.<sup>38</sup> Added to this, the development of E-commerce, such as the sale of pharmaceutical products over the Internet has implications of loss of revenue for the government, creating further disadvantages for those unable to access cheaper medicines. However, it also raises important questions about regulations regarding drug resistance, drug abuse and privacy of the patient, and so on.

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35 Policy Brief, CEHAT & JSA, 2004.

36 Pharmaceutical Industry: Globalisation will take away self reliance.

37 Ibid.

38 Amit Sen Gupta, *Health in the Age of Globalisation*.

In recent times, there has been a resurgence of communicable diseases like malaria, cholera, TB, plague, yellow fever, E.coli, which were thought to be “long conquered.”<sup>39</sup> This is a clear indicator of the degradation of the health status of people and the ineffectiveness of health services. Not surprisingly, therefore, “we have neither Health for All nor healthcare for all by the year 2000.”<sup>40</sup> Recent outbreaks of cholera in South Africa and Latin America have been linked with privatisation of clean water.<sup>41</sup> This is because most of the world’s global burden of disease and death is attributed to the failure to meet basic needs. Thus, accomplishment of the right to safe life is dependent upon the rights to food, clean water, sanitation, housing, education and work. However, the achievement of these is becoming increasingly difficult, as the Public Distribution System in India, which was introduced in 1965 to deal with the situation of rising food prices, is now totally inadequate. The recent NSS data shows that only 2 percent of the people in rural Bihar, UP, Orissa and Punjab are able to obtain PDS supplies.<sup>42</sup> In this situation where food security is disturbed and even water is on the verge of being privatised, the right to health becomes a parody in itself.

A strong campaign is needed to save the situation, rebuild self-reliance and achieve Health for All. The new social paradigm should be participatory in nature, taking into consideration the ‘felt need’ of those for whom it is devised. It should not have a beneficiary-client attitude, but should make the participants feel empowered and enable the community to take responsibility for their own health. Moreover, public health should be approached from a socio-epidemiological point of view rather than a biomedical and techno-managerial perspective. It can be achieved only through facilitation of information and favourable political and social order, which are sensitive to the demands and needs of the people. Moreover, right to health cannot be seen in isolation, and must be understood and realised along with the right to a safe life and the attainment of basic livelihood necessities.

*This chapter* deals with those concerns and problems related to ‘marginal groups’, which are often sidelined and neglected even within the larger debate of right to health. However, ironically, it is for this section of the population that right to health is not only sufficient but a necessary condition for living a life with dignity and self-esteem. Thus, it is an attempt to claim “protective discrimination” for marginal groups (including women, children, sex-workers, sexual-minorities, HIV-positive persons) so that everyone starts on an equal footing and has a space to voice their demands. The focus on these specific groups is not to prioritise the health issues of one community over others because ideologically we believe that right to health and healthcare is an entitlement of each person. Moreover, we are aware of the vulnerabilities of other groups like old people, tribals, dalits, physically and mentally challenged and feel their right to health needs special attention. The chapter

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39 Ibid.

40 A call for Action - Governments Take Responsibility for Women's Health, Primary Health Care and Women's Reproductive and Sexual Rights, WGNRR, pg. 7.

41 Sara Grusky, Bearing the Burden of IMF and World Bank Policies: Privatization Tidal Wave quoted in - A call for Action - Governments Take Responsibility for Women's Health, Primary Health Care and Women's Reproductive and Sexual Rights, WGNRR, pg. 4.

42 Reading Materials, Public distribution System: Perspective Projection, pg. 68.

does not cover specific issues like occupational health and mental health separately, although it explores and documents their linkages with other health issues. Given the space and the time it was not possible to highlight specific issues of each of these groups and all health issues. Moreover, in doing so there is an inherent danger of providing superficial explanations of complex and multifaceted problems.

## I. Women's Right to Health

The question of women's health is integrally linked with women's access to and control over resources, and with women's productive and reproductive roles in our society. While on the one hand resources are increasingly slipping out of women's control, on the other, they are being subjugated due to the gender inequities existing in the family and society. This double burden carried by women explains their chronic state of malnutrition, anaemia, stress, fatigue, and increasing mortality due to communicable diseases. Added to these are the pressures of modern life, poverty, environmental degradation and increasing violence.

The sufferings and indignation of an Indian woman today begins from the time she is in the womb, as is illustrated by the wide prevalence of sex determination tests and sex selective abortions, that further add to the odds that she has to struggle against in order to escape being discriminated against. It is a well-established fact that biologically women are the stronger sex. In societies where women and men are treated equally, women outlive men, and there are more women than men in the adult population. Typically, one can expect to find 103-105 women for every hundred men in the population. India is one of the countries where the situation is reverse. The 2001 Census records only 933 women for every 1000 men. With the sole exception of Kerala, every other State has fewer women than men. In the words of Nobel Laureate Amartya Sen, India, with its present population of 1 billion, has to account for some 25 million "missing women."

### Missing Women

If women and men were treated equally in India, we could expect that there would be around 105 women for every 100 men. Thus, in the present population of 1 billion, there ought to be 512 million women. Instead, estimates show only 489 million women in the population today. This implies that there are some 20-25 million "missing" women in India. Some are never born, and the rest die because they do not have the opportunity to survive.

The all-India Census data of 2001 clearly shows that the juvenile sex ratio in the age group of 0-6 has fallen by 18 points (from 945 in 1991 to 927 in 2001) and in states such as Haryana, Punjab and Gujarat, by over 50 points. Ironically, these are the economically more developed states in the country. According to a UNICEF report titled "The World Children's Report- 2000", discrimination against girls and women manifests itself in widespread incidence of sex-selective abortions. The report states how men and women, worried about the dowry costs in the future for a daughter, increasingly seek the services of traveling 'sonogram doctors.' According to the report, sex-selective abortion has been

reported in 27 of India's 32 states and singles out communities in Bihar and Rajasthan, where birth ratios are as low as 60 females for every 100 males. The violations of rights that women and girls face include a series of deprivations and different forms of discrimination that lower their chances of survival, including adequate nutrition and healthcare. Thus, even if the female foetus manages to escape gender bias in the womb, she may face infanticide, that is practiced in several communities of Punjab, Bihar, Rajasthan, Tamil Nadu and Uttar Pradesh.

### A real story

Lakshmi already had one daughter, so when she gave birth to a second girl, she killed her. For the three days of her second child's short life, Lakshmi admits, she refused to nurse her. To silence the infant's famished cries, the impoverished village woman squeezed the milky sap from an oleander shrub, mixed it with castor oil, and forced the poisonous portion down the newborn's throat. The baby bled from the nose, then died soon afterward. Female neighbours buried her in a small hole near Lakshmi's square thatched hut of sun-baked mud. They sympathised with Lakshmi, and in the same circumstances, some would probably have done what she did. For despite the risk of execution by hanging and about 16 months of a much-ballyhooded government scheme to assist families with daughters, in some hamlets of ... Tamil Nadu, murdering girls is still sometimes believed to be a wiser course than raising them. "A daughter is always a liability. How can I bring up a second?" Lakshmi, 28, answered firmly when asked by a visitor about how she could have taken her own child's life eight years ago. "Instead of her suffering the way I do, I thought it was better to get rid of her." (Taken from "Where killing babies is no big sin" by Dahlburg, The Los Angeles Times, quoted in the Toronto Star, February 28, 1994).

A number of research studies<sup>43</sup> and field accounts observe that access to nutrition and healthcare is disproportionately tilted in favour of boys and men, which in turn impacts gender differentials in mortality. Dr. Malavika Karlekar, a well regarded social scientist, writes of a definite bias in feeding milk, milk products and eggs to boys. In Rajasthan and Uttar Pradesh, it is usual for girls and women to eat less than men and boys and to have their meal after the men and boys have finished eating. In case of illness, usually boys are given preference in healthcare.<sup>44</sup> This is true for women and girls of almost all communities. The additional biological demands on women due to menstruation, pregnancy and lactation further accentuate the situation, making nutritional deficiencies the most widespread and disabling health problem among women in developing countries. Iron deficiency anaemia makes pregnancy and delivery high-risk and life threatening events for women. A vicious cycle of under nourishment and ill health is set in motion: poorly nourished mothers give birth to low birth-weight babies. Low birth-weight babies have 3-4 times greater risk of dying from diarrhoea, acute respiratory infections, and if not immunised, measles. Baby girls born with a low birth weight are, in addition, likely to be disadvantaged in terms of feeding and care, and grow up to be severely undernourished adult women in poor health. This, in our understanding, is heinous violence against humanity and gross violation of rights, which has an adverse effect on women's health throughout their lives.

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43 Miller, 1981; Arnold et al, 1996; Bardhan, 1974, 1982; Kishore, 1993, 1995; Kurz and Johnson-Welch, 1997; Waldron, 1987; Makinson, 1994; Obermeyer and Cardenas, 1997.

44 Malavika Karlekar, "The Girl Child in India."

Neglecting these larger determinants of women's health altogether, the existing policy reflects a strong patriarchal bias, and limits women's health to pregnancy and childbirth. Thus, often communicable diseases like malaria, tuberculosis, and reproductive health problems such as reproductive tract infections, white discharge or prolapsed uterus, to name a few, get neglected.

Women can rarely access treatment for these complications. Firstly, all the other problems of access mentioned earlier, hold true for women as well. Further, due to their marginal status in the family and the stigma attached to reproductive and sexual health in society, they suffer silently. Besides, the public health facilities, especially in the rural areas are poorly equipped to deal with reproductive and sexual health issues. Female gynaecologists are rare, making it difficult for women to discuss these issues in a public space.

There is also a lack of sensitivity to understand that communicable diseases affect women and men differently. Although both men and women are equally exposed to communicable diseases, there are concrete evidences to show that women suffer far more than men in terms of decision-making and access to treatment and services. There exist crucial linkages of communicable diseases - particularly TB and Malaria, perhaps because they are so common - with issues related to poverty, the decline in access to natural resources, environmental degradation and the change in lifestyles and food habits, to name a few.<sup>45</sup> These larger linkages are unfortunately neither addressed in policies, nor acknowledged by health providers. In fact, gender is the most neglected component in the entire discourse on health, even though several studies poignantly underline these linkages.

Women also often lack the authority to make healthcare decisions for themselves. Where women's health is low on the family priority list, decisions regarding healthcare for communicable diseases, general illness, pregnancy and pregnancy related complications could be delayed, often with dire health consequences (Jejeebhoy 2000: 161). There is also evidence that women wait longer than men to seek care for illness partly due to their unwillingness to disrupt household functioning until they become incapacitated (Kaur 1997). There is also evidence that female children below four years displaying symptoms of pneumonia were not taken to a health provider or given any treatment at home as compared to similarly affected male children in this age-group.

An additional threat to women's health is the overwhelming focus of the public health system on birth control, the primary targets of the Family Planning programme being women. Women's bodies are increasingly becoming targets for research, trials and aggressive marketing of new reproductive technologies, all of which results in traumatic side effects and are potentially hazardous for the well-being of women in the long-term.

The wide ranging technologies under the umbrella term New Reproductive Technologies (NRTs)

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45 Interrelationship between Gender and Malaria, Research Proposal by Sama-Resource Group for Women and Health, 2003.

comprising both contraceptive and reproductive technologies raises important issues about the interface of technology, health, women and society. Many proponents of mainstream population policies would unequivocally support these technologies as the effective solution for women's problem of having unwanted children. Providers of assisted reproductive technologies, like In-Vitro Fertilisation (IVF), surrogate motherhood, embryo transfer, would similarly argue that they expand choices for infertile individuals and couples. However, the question is to explore in what possible ways do these technologies pose a threat to the Right to Health dictum, specifically the Right to Reproductive Health.

WHO defines Reproductive Health as "a state of complete physical mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and its function and processes...People are able to have satisfying sexual life and they have the capability to reproduce and the freedom to decide if, when and how often to do so"<sup>46</sup>.

The new reproductive technologies, both the new hormonal contraceptives and the assisted reproductive technologies, have gained considerable attention from technology developers and policy makers. However, there is constant neglect of the side effects of these technologies. A recent incident in Calcutta underlines the risk of HIV/AIDS in having a baby through semen donation.<sup>47</sup> These new technologies require prior medical examination and continuous monitoring, as well as back-up systems to deal with severe side effects and health dangers. In India, such conditions are hardly ever adequately addressed due to poor health infrastructure, abysmal health services along with ingrained gender biases and an overwhelming slant towards birth control.

The terrain of contraceptive and assisted technology is also flooded with cases of clinical trials and abuse of women as objects and non-participants. Although international developers have become much more sensitive to the issues of abuse in clinical trials, many guidelines are breached when the targets are illiterate women from marginalised classes, castes and tribes from the Third World. The inhuman treatment and non-consensual medical and scientific experimentation mindlessly violate the guidelines of informed consent, equal treatment, testing of new technologies, reproductive health measures, as well as the right to information.

Though the questions of choice and empowerment are often the keywords for policy formulation and propagation of NRTs, in reality these hardly exist. This is because the right to reproductive health demands a basic framework where equity, if not equality, must exist. However, the concern with "context"<sup>48</sup> has been downplayed by the developers and propagators of reproductive technology research. The most central aspect of the context, which governs the relationship between reproductive technology and its end user, is gender compounded by class, ethnic origin, caste or other social

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46 Source: World Health Organisation, Para 7.2.

47 Times of India, 2003.

48 *Rights and Reproductive Technologies*, Gita Sen.

relations of power. As long as these underlying currents are not identified and acknowledged, the concepts of choice, empowerment or rights will only remain words on paper; and technologies will continue to propagate gender biases either through sex-detection or sex- pre-selection.

In this situation, it is absurd to expect respect for bodily integrity, equality, control over sexuality and fertility, freedom of sexual expression, safe sex and safe reproduction. Rather, in this paradigm, NRTs can pose serious threat to Right to Health by going against -

- Reproductive security and sexuality.
- Reproductive health.
- Reproductive equality.
- Reproductive decision-making.<sup>49</sup>

However, to benefit from technologies, it is important to focus on the wider determinants that shape the lives of women (and men). These wider determinants not only include poverty and quality of health services, but also gender and other social biases, as well as strengths of civil society's institutions. This is because the NRTs not only impinge upon the reproductive health of women, but also on the overall physical and mental health of women, as well as the health of the entire society. These technologies not only jeopardise women's right to health, but also right to life, safety, security and dignity.

### ***Violence against Women and Health Consequences***

Apart from the inaccessibility of quality care and the flaws that exist in policy formulation, women suffer incessantly from familial, social and state violence and also from degrading working conditions in terms of both infrastructure and attitudes of people. It can be said, "When it comes to violence against women, there are no 'developed' countries."<sup>50</sup> In the public discourse<sup>51</sup> all over the world however, the concern for violence against women and children has been conspicuous by its very silence. This is so because atrocities are always covered up either by the woman herself, the family, the community or the State under the uncontested belief that whatever the merits of the case, the women must have been the provocateur and hence she deserves it. Even the violence inflicted upon the girl-child and women are justified by the legal system, medical system and judiciary, and hence are taken as the last site for concern and public action. While one does not want to sensationalise and embellish the phenomenon of increasing violence in our society, one also cannot refrain from saying that for the healthcare services it is a huge, but ignored, "epidemic"<sup>52</sup> of the present times. Violence

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49 *Reproductive Rights as Human Rights: Studies in the Asian Context*, Asia Forum for Human Rights and Development, 1998.

50 Charlotte Bunch, Center for Women's Global Leadership [3], quoted in "Violence, Pregnancy, and Abortion - Issues of Women's Rights and Public Health" by Marie de Bruyn Policy Division, 2001.

51 Most part of this account on Violence on Women and Right to Health was published as "Why and how is violence against women of concern to healthcare providers?" by Nandita Bhatta and Anuradha Rajen, ICRW.

52 Amar Jesani, Neha Madhiwalla, *Violence and Healthcare profession in India: Towards a Campaign for Medical Neutrality*.

against women and girls is one of the most pervasive and debilitating forms of human rights violations. It has been defined by the United Nations in the Declaration on the Elimination of Violence against Women (1993) as:

“Any act of gender-based violence that results in, or is likely to result in physical, sexual or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.”

- The World Health Organisation has declared that violence against women causes more death and disability in the age group of 15-44 years than cancer, malaria, traffic accidents and war combined.
- According to a household level study on domestic violence in India (INCLIN, 2000), 50 percent of married women reported facing spousal violence and among those reporting abuse, 50 percent reported abuse during pregnancy.
- Almost 16 percent of deaths in pregnancy were caused by domestic violence according to a community and hospital based prospective study in Maharashtra, India, conducted during 1993-1995.<sup>53</sup>
- According to a study done by the World Bank, rape and domestic violence emerged as a significant cause of disability and death among women of reproductive age in both the industrial and the developing world. In established market economies, gender-based victimization accounts for nearly one in five healthy years of life lost to women age 15 to 44.<sup>54</sup>
- Violence against women refers to a range of acts varying from physical abuse (hitting, kicking, punching, slapping, beating, starvation, burning etc.), psychological abuse (verbal abuse, threatening the woman, not allowing her to meet others, humiliating the woman in private or public, etc.), sexual abuse (rape, forced sex, sexual coercion, sexual harassment, marital rape etc.) to a host of other ways by which a woman's personal security may be seriously compromised. In India, women also face financial abuse if the husband/ 'bread-earner' abandons the wife and children or does not allow her access to any money by retaining all financial control. Social norms and cultural practices in India are rooted in a highly patriarchal social order where women are expected to adhere to strict gender roles about what they can and cannot do. Article 2 of the UN Draft Declaration states that violence against women shall be understood to encompass, but not be limited to the following:

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53 Ganatra BR, Coyaji KJ, Rao VN, *Community cum Hospital Based Case-control Study on Maternal Mortality: A Final Report*. Pune, India: KEM Hospital Research Centre; 1996.

54 Heise, L. 1994, *Violence Against Women: The Hidden Health Burden*. World Bank Discussion Paper. Washington DC : The World Bank.

- ❖ Physical, sexual, and psychological violence occurring in the family, including battering, sexual abuse of female children in the house-hold, dowry-related violence, marital rape, female genital mutilation, and other traditional practices harmful to women, non-spousal violence, and violence related to exploitation.
- ❖ Physical, sexual and psychological violence occurring within the general community, including rape, sexual abuse, sexual harassment and intimidation at work, in educational institutions and elsewhere, trafficking in women and forced prostitution.
- ❖ Physical, sexual and psychological violence perpetrated or condoned by the state, wherever it occurs.

In this context, violence is one of the tools used to reinforce women's subordinate status - to control the oppressed or disempowered. It is a way of asserting control and power. Thus domestic violence (commonly referred to as 'wife beating') is justified by society if the wife is found not attending to household tasks adequately, not caring for her husband or on grounds of suspicion (see NFHS 2, Visaria 1999, Rao *et al* 1996). Contrary to popular belief, rape and sexual assault are not always crimes of passion, neither do they always occur under the influence of alcohol. Children from the age of 2 months to women of 85 are raped. According to police reports from Delhi, the rapist is most frequently not a stranger but someone from the victim's immediate family or neighbourhood. In caste wars and ethnic conflicts, rape of women is often used as a weapon to punish and dishonor the other community. Women's bodies thereby become sites of revenge. This was very pronounced in the recent Gujarat carnage when raping and sexually assaulting women of the minority sections became a "heroic" deed to be praised and emulated. While these acts are performed in order to teach men a lesson, women suffer physically and mentally.

These acts reflect that nowhere in the patriarchal discourse do women's bodies appear as their own, but like a property, they are in the possession of male guardians, and are ravaged in order to teach other men a lesson. These devastating life experiences threaten the life of women both physically and mentally, because this questions the integrity of their body and mind. They also suffer from a lingering feeling of shame and guilt as they are made to believe that women always invite rape. The genocide that took place in Gujarat was a "crime against humanity."<sup>55</sup> By all accounts the centrality of sexual violence in this entire massacre deserves special mention. The physical impact of the sexual violence against women is enormous: Polymenorrhea, Dysmenorrhea, chronic vaginal discharge etc.<sup>56</sup> Added to this is a constant mental tension and pain surfacing both from the experienced turmoil and from the lingering impending threat.

It thus becomes very important to take stock of this very common yet under-reported form of violence, namely **sexual assault or sexual violence**. Sexual violence exists along a continuum, from forcible

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55 *Threatened Existence: A Feminist Analysis of The Genocide in Gujarat*, International Initiative For Justice, December 2003.

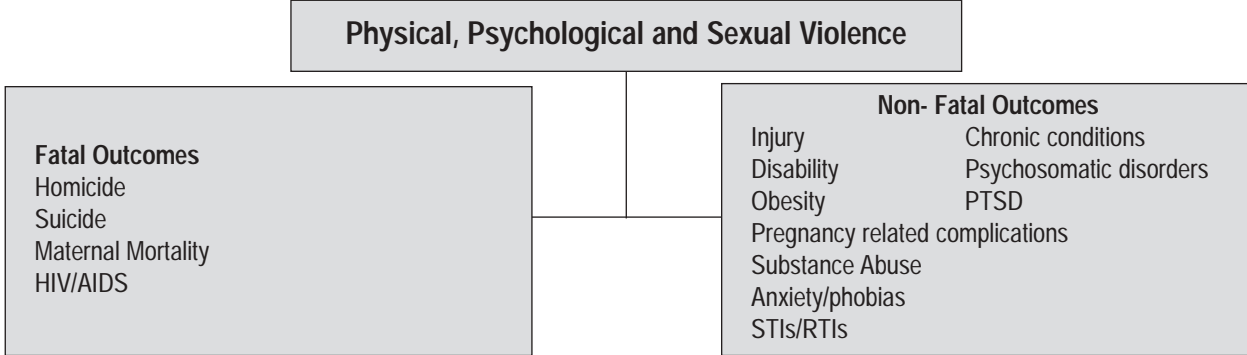
56 Medico Friend Circle, *Gujarat Carnage and the Health Services: A Public Health Disaster*, May 2002.

rape to non-physical forms of pressure that compel girls and women to engage in sex against their will.<sup>57</sup> Child sexual abuse is a very common form of sexual violence that young children and girls in particular face. However, there is a wall of silence around this issue in many societies including ours. Facing sexual abuse as a child or in adulthood places women at risk of substance abuse (alcohol and drug addiction) and engaging in sexually risky behaviour. Both these conditions have serious consequences on their mental and physical health.

Sexual abuse can lead to unwanted pregnancies, sexually transmitted diseases, including HIV/AIDS and reproductive tract infections. Women’s ability to negotiate safe sex with their partners is severely restricted due to several factors. Women are expected to be ignorant about matters relating to sexual activity and assume a passive role in sexual activity. According to a research study conducted across several countries in the world,<sup>58</sup> one of the barriers women face in suggesting condom use is fear of a violent reaction from their partners. The study found that female STD patients participating in focus groups and in-depth interviews in South Africa reported that they were able to initiate general discussion on HIV/AIDS but not on condom use. One woman said, “If I just mention the word condom, he will hit me.” This has also been witnessed quite often in Sama’s interaction with community health workers who have expressed similar concerns about negotiating condom use with their partners who often associate it with promiscuity.

Violence during pregnancy can lead to a range of health complications, ranging from premature labour, increased risk of miscarriages and abortions, and foetal distress. Several studies also have focused on the relationship between violence in pregnancy and low birth weight, a leading contributor to infant deaths in the developing world.<sup>59</sup> Along with these familial and communal violence, women are often unprotected from State inflicted violence in diverse settings - ranging from mass sterilisations under family planning programmes, to brutal physical and sexual assault in mental hospitals and in prisons.

Some of the significant health outcomes of violence may be diagrammatically represented as follows:



57 Population Reports, Volume XXVII, Number 4, December, 1999. Published by Johns Hopkins School of Public Health and CHANGE.  
 58 *Bridging the gap, Addressing gender and sexuality in HIV Prevention*; Ellen Weiss and Geeta Rao Gupta, ICRW, 1998.  
 59 Population Reports, Volume XXVII, Number 4, December 1999. Published by Johns Hopkins School of Public Health and CHANGE.

It is critical therefore, to begin viewing violence against women as a public health issue. And healthcare providers such as doctors, nurses, medical and psychiatric social workers, psychologists, physiotherapists etc., can play a critical role in screening patients for assault as well as referring them to appropriate agencies for help. Doctors and other health professionals till now have by “omission or commission”<sup>60</sup> obscured women’s voices, neglecting to record the women’s testimonies, by not recording that the injuries have occurred due to violence or even by raising doubts about their sexual history and character. These attitudes need to be changed. Studies worldwide have shown that hospitals and clinics, whether government owned or private, are an important entry point for women suffering from abuse within the family.

Thus, women’s health is jeopardised by diverse societal forces, the root of which lies in the discrimination that exists in society. There is an urgent need to sensitise and promote men’s understanding of their roles and responsibilities, to ensure that women’s rights and empowerment is sustained. However, while “discrimination” is not defined in the Covenant, its meaning is ascertained by reference to the usage developed in the references and interpretation of other international human rights instruments. The definition of discrimination against women in the Convention on the Elimination of All Forms of Discrimination Against Women (Women’s Convention) encompasses a broad range of issues. Article 1 provides:

The term “discrimination against women” shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on the basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

Underlying determinants such as lack of nutrition, prejudice and violence affect women’s lives both physically and mentally. The significance of bodily integrity and self-determination, including health, wellness and sexual pleasure as inseparable from men and women’s full and equal participation in all aspects of social life should be the focus of the approach to right to health. The principle of equality along with economic, cultural and social rights which lead to sustainable development, environmental preservation and peace<sup>61</sup> can alone ensure Health for All irrespective of gender. The promotion of the responsible exercise of these rights should be the fundamental basis for government and community - sponsored policies and programmes.<sup>62</sup> It should be endorsed by information and service mechanisms that meet the full range of general health, sexual and reproductive health needs in an atmosphere that fosters safety, non-discrimination, privacy and confidentiality. Thus, the need is not only to

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60 Amar Jesani, Neha Madhiwalla, *Violence and healthcare Profession in India: Towards a Campaign for Medical Neutrality*.

61 Rhonda Copelon and Rosalind Petchesky, *Toward an Interdependent Approach to Reproductive and Sexual Health Rights as Human Rights: Reflections on the ICPD and Beyond*.

62 Beijing Platform for Action, 1995.

incorporate a biomedical understanding of health and illness but also to be sensitive to the larger determinants of health at the level of the family, community and society. It is only then that the dictum of Right to Health will materialise in reality.

## **II. Children's Right to Health**

As discussed earlier, human rights encompass rights related to all the major socio - economic - political determinants of health. These are even more significant and complex in the context of children because they necessitate the existence of empowered adults and families for their actualisation. Thus, as far as children are concerned, violations may affect them directly or through the impact on family and parents, making them many times more vulnerable. Simultaneously, by dint of their age and developmental process, children's health is more vulnerable than adults' and the impact on their health is also more dramatic and far reaching.

Historically, the main issues of concern to human rights activists working with children have been the trafficking of children for prostitution or bonded labour, children in labour, children in homeless situations, children in armed conflict including communal violence and children in institutions. Another important category of marginalised children is of children with disabilities or special needs.

However, before looking at these categories from the point of view of the right to health, it is worthwhile reiterating the fact that the denial of basic rights to food, shelter, healthcare and care in general are appalling child rights violations that have been in existence for so long as to be tacitly accepted as irremediable by governments and policy makers.

India's track record on child malnutrition, infant mortality, under five mortality continues to be unacceptably poor disregarding small pockets of high achievement. Simultaneously, programmes such as the ICDS, school health programmes and the universal immunisation programmes have inadequate budgets, low priority and poor delivery resulting in a plateauing of impact. Millions of children continue to be out of school and labouring for wages at great cost to their health and development.

The children of over 180 million women labouring in the informal sector do not have the privilege of being supported by maternity entitlements. The provision of crèches on worksites is still a distant dream even though mandated by some laws related to construction work and work on plantations and mines. As a result, children are denied even the right to be breast-fed. The same holds true for the third child in a family with increasing violations of his /her rights by the 'two child norm' being set into law and policy. Sex selective abortions, discussed in an earlier section, are a serious violation of the rights of girl children and women to exist as a race. Early marriages are still very common and 36 percent of children in the age group 13-16 years are married. Consequently, an alarming 64 percent of the girls in the age group 17-19 years are already mothers. This has an adverse impact on the health of both mother and child.

Human rights activists must see these as violations of children's human rights by the State by acts of omission as well as commission. The brutality of allowing children to suffer and die in dire poverty while a small segment of India prospers, should not be underplayed.

Some specific situations of human rights violations in children and their impact on health are discussed below:

### ***Child Labour***

The quantification of children in labour has always been a problem with large variations between State and NGO figures (11-100 million!). However, it would not be incorrect to estimate this figure at close to 80 million children who are not able to avail of education because they are in wage labour. Even informally, every single poor child spends a great deal of time and energy helping the family to survive by performing tasks of fetching water, carrying other heavy loads, doing much of the housework, being sole caretakers of younger siblings and helping out in family owned or home based small enterprises.

Undoubtedly, this is a factor in the situation of malnutrition that impacts practically every poor child; the combination of insufficient food and leisure, and greater caloric requirements being devastating.

Where a child working for wages is concerned, the situation is far more serious and reprehensible. The miserable conditions of labour have been documented repeatedly. Safety, hygiene and protective labour laws are completely ignored. Children work long hours without breaks in dark, dingy, damp, unsafe conditions. Beatings and sexual harassment are the norm. Wages are pitiable. The effects on growth, general health and development are not difficult to imagine.

The industries and occupations that have been found to commonly employ children include beedi, tobacco, electronics, brick kiln, carpets, match and fireworks, bangle making and domestic work. Specific occupational hazards include symptoms of tobacco dust exposure (vomiting, fatigue, anorexia, headache), deafness from exposure to noise, bone and joint deformities from sitting in abnormal postures for prolonged periods, heat stroke and respiratory diseases in brick kilns, metal fume fever from exposure to zinc oxide and phossy jaw from exposure to phosphorus in the match industry. Skin problems are extremely common in children involved with prawn farming due to chronic exposure to water and sharp materials.

The plight of the female domestic worker is unimaginable - she has a 24-hour working day, suffers beatings severe enough to cause fractures and death and often gets assaulted and raped in the bargain, all for a miniscule wage and sometimes only for food and lodging.

### ***Child Trafficking and Street Children***

The reasons and forms of trafficking include bonded labour, prostitution, religious prostitution, pornography, sex tourism, begging, organ trading, drug peddling and smuggling, selling to dance and theatre troupes and circuses, adoption, 'marriage' and 'exporting' for camel racing.

Apart from completely violating a child's right to childhood and a decent life, specific health hazards include multiple teenage pregnancies and abortions, STIs, HIV/AIDS, exposure to drugs, accidents, physical and sexual abuse by employers and the police, disfigurement, mutilation, castration and removal of various organs.

Experiences of street children in the various metropolises of the country present an identical picture. Gastroenteritis, skin diseases, STIs, heat exhaustion and heat stroke, exposure to severe cold temperatures is very common. Experiences also reinforce the fact that mental disorders and drug addiction are so common as to be the norm. Severe depression and despair, anxiety, Post Traumatic Stress Disorder (PTSD) and other neuroses dominate. Needless to say, that the situation of general health and growth is poor with limited access to hot meals combined with high spending on drugs, alcohol, tobacco and other escape mechanisms like movies. In all these categories, severe health problems are compounded by the fact that there is practically no access to healthcare facilities.

Child trafficking through processes of adoption has been exposed as a racket in many parts of the country including Andhra Pradesh (Lambada tribal community), Goa (related to paedophile rackets) and Orissa. In many of these cases, NGOs have also been shown to be involved. Some of these children land up in sex and pornography work and domestic labour. Though there are arguments for and against inter country adoption and one would not like to denigrate adoption as a way of protecting the rights of children in certain circumstances, the lack of proper regulatory mechanisms to ensure that this does not become another method of human rights violations needs to be addressed. The other 'health concern' in the context of adoption is that adoptive parents are still not granted maternity entitlements by law. There can be no defense of this position since adopted children need all the care that natural born children need, if not more, in the early months of this new relationship.

It is worthwhile to also recognise the fact that trafficking of children is related to conditions causing large scale displacement and migration such as natural disasters, communal riots and ethnic strife which in themselves have a severe impact on the health of children causing physical and emotional trauma, exposure to diseases like typhoid, cholera and gastroenteritis and malnutrition due to food insecurity.

### ***Children with Disabilities***

An enormous 3-10 percent of children in India may be suffering from some physical or mental disability. However, identification and outreach extends to a tiny number amongst them. Services such

as special schools for the visually and hearing impaired, special aids etc., are available to a still smaller number. According to the sixth educational survey, 1999, of the total 586,465 villages in the country, only 241 have any institutions with facilities for children with special needs. Access to health services including physical access is a special problem. The stigma attached to disability of any kind, especially in the girl child adds to the emotional health problems and marginalisation of these children.

The Persons with Disabilities Act, 1995, attempts to protect the rights of persons with disabilities and integrate children with disabilities in mainstream educational institutions. In reality the mainstream system of education really does not have the required flexibility, nor is there adequate training to deal with the integration of children with special needs which invariably takes a back seat.

The nutritional problems of children with disabilities tend to be more severe for a variety of reasons and contribute to their greater susceptibility to illness and this often compounds their handicap. Health professionals like obstetricians and pediatricians are also inadequately prepared for the early identification and management of developmental disorders.

### ***Children and HIV / AIDS***

It is difficult to compute the number of children affected by HIV/ AIDS; either in the sense of being infected, or having parents who are affected or being orphaned because of the disease. According to NACO estimates on the basis of prevalence, 55,000 children are already infected with HIV /AIDS by the year 2003. Of course, many more would have a parent or parents who are affected and there are many who have been orphaned due to this.

Apart from the economic and emotional consequences of being children in families with HIV/AIDS or having HIV/AIDS, these children are often discriminated against where educational and health services are concerned. Consent and confidentiality issues are even more complex and open to being ignored where children are concerned. The requirements of social security and institutions for care when required need serious consideration.

HIV /AIDS in children is closely linked to their vulnerability in situations of living on the streets, being in prostitution or other scenarios of sexual abuse, child labour and conditions involving displacement and migration. The other 'rights' issue concerning children and HIV/AIDS is the right of the adolescent to access reproductive health information and care well before they become sexually active.

### ***Children in Armed Conflict and Communal Strife***

Children in Jammu & Kashmir and the Northeast have been used by militants to fight and have also been injured or killed in crossfire. The recent pogrom in Gujarat was evidence to the use of violence against women and children as a strategy to express hatred. Survivors in camps for the 'riot affected'

suffered further deprivation, hunger and disease. Long-term effects on mental health including depression and PTSD are still being observed amongst these children. As pointed out earlier, these conditions also lay the ground for child trafficking.

### III. The Right to Health and HIV/AIDS

*How AIDS has been theorised has had profound implications, not only for how we understand the disease, but also for our responses to it (Karen Lee and Anthony).*

#### *The AIDS Scenario in India*

Almost 58 million people throughout the world have been infected with HIV and almost 22 million people have died. HIV continues to spread, causing more than 15,000 new infections every day. Official estimates put the number of HIV-positive people in India at approximately 3.9 million, a tenth of the world's prevalence. There is an estimated 50,000 to 1,00,000 AIDS cases in the country. However, the official figures tell a different story. According to the HIV/AIDS surveillance report, in India there are 44,275 AIDS cases (NACO updated as on 28th February, 2003) of which, 33,055 cases are found among men and 11,230 cases among women.

In India, the first AIDS case was detected in 1986 in Chennai. The latest data suggests that HIV infection has spread into almost all Indian states and union territories. Throughout the country, persons in traditionally high risk groups i.e. women in sex work, injecting drug users, and men who have sex with men, have been shown to have alarmingly high rates of infection (Human Rights Watch, 2002). Today, the epidemic is seen to be shifting towards women and young people; also, there is an increase in paediatric HIV infections. Currently, the HIV infection rate in the adult population in India is 0.7 percent (NACO: 1999-2000; cited in Kurian, 2002). Because of the size of India's population, even a mere 0.1 percent increase in the prevalence rate would increase the number of adults living with HIV/AIDS by over half a million people.

In India, the official response to HIV/AIDS started in the initial stages, in 1985, with the ICMR setting up a Working Group to monitor the situation. It started HIV testing for surveillance with the focus on high-risk groups, a perspective it had imbibed from the image of the disease generated in the West. Thus, the Department of Health, Government of India set up the National AIDS Control Programme (NACP) in 1987. During the 1987-1992 phase, the NACP was operative with technical support from the DGHS and funding by the Indian government. The government also introduced a Bill in the Parliament (based on the century old Epidemics Act) proposing isolationist measures for HIV-positive people, in order to protect the rest of the society. There was no concern for the rights of affected people or society's obligation to take care of its ill members. Guidelines of the ICMR Working Group, for diagnosis and treatment of HIV-positive persons included maintaining confidentiality and giving counseling but waived the necessity of 'consent' by the patient on the plea that "our illiterate population cannot understand the issues" (Ritupriya; 2002).

In 1992, the official programme took a leap, with increased funding due to a World Bank loan and bilateral international aid. The scale of NACP expanded, and the institutional structures of the NACP were isolated from others of the Department of Health by creating a separate National AIDS Control Organisation (NACO). While the NACO was to deal with policy decisions, programme structure and capacity building for dealing with AIDS, implementation was to be through the existing public health services for surveillance, both public and private sector for blood banks, and NGOs for IEC and condom promotion. It is important to note that capacity building for care and support was still not a priority, though training of healthcare providers did figure in the list of activities.

Since it was essential to have a fairly good idea of the number of HIV infected cases in the country for the control and prevention of HIV, a surveillance system was set up in 1994 with 55 surveillance sites in various parts of the country (NACO 2000 - 2001). Later, the surveillance system was expanded, and in the year 2000 there were 232 sentinel sites in India - 109 sites in clinics for STIs, 110 in antenatal clinics, 11 sites among intravenous drug users and 2 sites from areas frequented by men having sex with men. These sites and population groups were chosen based on information of risk behavior for HIV infection.

In India, most of the information on HIV infection comes from the Sentinel Surveillance data. The National AIDS Control Organisation, based on the 2000 sentinel surveillance data, classified Indian states/union territories into three major groups based on the HIV prevalence in adult population. The various groups of states are the following:

**Group 1** - includes states like Maharashtra, Tamil Nadu, Karnataka, Andhra Pradesh, Manipur and Nagaland where the HIV infection has crossed 1 percent or more in antenatal women.

**Group 2** - includes states like Gujarat, Goa and Pondicherry where HIV infection has crossed 5 percent or more among high risk groups but the infection is below 1 percent in antenatal women.

**Group 3** - includes remaining states where the HIV infection in any of the high-risk groups is still less than 5 percent and is less than 1 percent among antenatal women.

It can be inferred from the Sentinel Surveillance data from antenatal clinics in 7 metro cities in the country, that HIV infection has crossed 2 percent in Mumbai, is more than 1 percent in Hyderabad, Bangalore, Chennai and is below 1 percent in Calcutta, Ahmedabad and Delhi. It is important to note that in India the major mode of HIV transmission is through heterosexual contact; over four-fifths of the infections are by this route. The second most common mode is through blood transfusion. However, HIV infection through blood transfusion, perinatal transmission, and homosexual contact is very low in India. Data on HIV prevalence among men who have sex with men is scarce, which some experts attribute to the government's denial of the fact that men have sex with men in the country. But lately, injectable drug use has developed as a major concern, as the prevalence of HIV among this

section enhanced significantly (Sen, 2003).

About 89 percent of the reported cases are from the sexually active and economically productive age group of 15-49 years. Over one in every three reported cases is a woman. The HIV prevalence in India is reported the highest among sex workers, intra venous drug users and patients suffering from STIs. The above details also indicate that the HIV/AIDS infection has so far made its way mainly into the southern and the north-eastern states. Some claim that better data collection in the southern states is the reason for the higher HIV/AIDS prevalence (Mehendale 2000, cited in Stones and Pallikadavath, 2003). Although the HIV/AIDS infection has reached close to four million people in India, no HIV testing or treatment is offered under the government public health system.

### ***Why do we need to talk about HIV/AIDS within the purview of “rights” discourse?***

In the present times, the AIDS pandemic has opened a Pandora’s box. The central challenge facing HIV/AIDS prevention efforts today is to understand and learn how to respond to the societal determinants of vulnerability to HIV. The difficulty that states, communities and individuals face in confronting the HIV pandemic lies in the fundamental but difficult issues it raises - like issues of sex, sexuality, diversity, ‘nonconformist’ behaviour, inequality in all kinds of spheres i.e. gender relationships, access to goods and services, employment and wealth. This is an epidemic that knows no borders of geography, class, caste, gender and sexuality (ed. Grover, Kukke, and Bharadwaj; 2003). With the infection being one which is transmitted through unprotected sexual intercourse, mother to child or through blood or bodily fluids, it is likely that these numbers will increase manifold in a very short time, creating a social, economic and health crisis in the country.

Needless to mention, certain interventions have to be made which will reassess and re-examine not only public health services and policies (due to the tremendous prejudice that the epidemic creates in people’s minds) but also that address the human rights of affected persons and the legal regime which governs their needs. Once we have determined that for HIV/AIDS, as for all other health problems, the major determinants are societal, it is important to be clear that since society is an essential part of the problem, a societal-level analysis and action is required. The public health paradigm- considers that both disease and society are so interconnected that both must be considered dynamic. An attempt to deal with one, the disease, without the other, the society, would be inherently inadequate.

### ***HIV and Public Health Approach***

Initially two diametrically opposed public health responses arose internationally in the HIV/AIDS context - the isolationist and integrationist responses. The isolationist response postulated three fundamental strategies:

- Compulsory or mandatory testing of all.
- Breach of confidentiality of those found positive.
- Isolation from larger society through discriminatory practices.

The integrationist strategy was based on a contrary view:

- Voluntary testing based on the informed consent of persons.
- Non-disclosure of their positive status.
- Equal and fair treatment to them in healthcare, employment and all other facets of life (Colloquium, Lawyers Collective; 2002).

Integrationist policies are based on the fundamental human rights of individuals to self-autonomy, privacy, and equality. The basis of this philosophy is that in the long term, voluntary testing, confidentiality and non-discrimination would encourage people to come out and access health services thus increasing the possibility of instilling behaviour change and personal responsibility through counseling, and thereby reducing the spread of the virus. The integrationist approach, therefore, sought to battle and reduce stigma whereas the isolationist approach sought to increase it, thus pushing the problem further underground. Earlier the isolationist response was felt to be most appropriate, as it demanded the disclosure of the positive status of persons. This approach was adopted by most legal regimes until its negative consequences became obvious. It was realised that isolation versus integration was not an issue of public versus individual interest. Instead, the protection of the individual was itself in the public interest as it increased accessibility to services and brought the epidemic into the open thus enabling effective public health interventions (ibid). Therefore, India has now begun adopting integrationist policies.

Public health, as a state function, is obligated to respect human rights and dignity. However, the traditional public health paradigm and strategies developed for diseases such as smallpox, often involved coercive approaches that may have burdened human rights, are now understood to be less relevant. Recently, in the context of HIV/AIDS, new approaches have been developed, seeking to maximise realisation of public health goals while simultaneously protecting and promoting human rights.

### ***The shifting HIV / AIDS paradigm***

Initially, the HIV epidemic was defined through a medical paradigm traditionally applied to infectious disease control. If people are aware of risks and are given the means to protect themselves from these risks, the popular notion is the epidemic would be controlled. In 1986, the World Health Organisation launched a global strategy against HIV/AIDS in response to the outcry from people affected by HIV that they suffer from both the health consequences of the infection and intense discrimination. Thus,

the protection of human rights of people living with HIV/AIDS forms an intrinsic part of the initial WHO Global Strategy (Tarantola 2000).

From a public health perspective, there are two pragmatic reasons why human rights figured so prominently in the strategy:

1. HIV-infected people are discriminated in their access to essential care, support, and livelihood.
2. Discrimination discourages individuals at risk from seeking HIV testing and counseling, and from playing an active role in prevention.

Nevertheless HIV continues to spread unchecked among people who enjoy few of their civil, political, economic, cultural, and social rights. The epidemic increasingly and disproportionately impacts the poor and the marginalised. The true dimensions of the linkages between HIV and human rights became clearer in the early 1990s. The realisation of human rights is indeed critical to the survival and dignity of people living with HIV. It is also a crucial component in reducing the risk of acquiring infection among those whose vulnerability is determined by inequalities and stigma associated with a host of attributes, including gender, social and economic status, and sexuality.

The global response to HIV has expanded beyond the original medical paradigm. This paradigm addresses factors such as gender inequality, economic disparity, mobility, and insecurity. The “risk-vulnerability” paradigm developed in the early 1990s, grounded in health and human rights principles provides a comprehensive and clearer perspective of the determinants of the spread and impact of HIV. This has helped to redefine the HIV epidemic (ibid).

While no one appears to be denying the importance of prevention and of the reforms needed to reduce vulnerability to HIV, the emerging emphasis on care is raising new issues of access to services and technologies, distributive justice and human rights.

The Universal Declaration of Human Rights, adopted by the UN General Assembly in 1948, provides societal conditions considered essential for well-being, peace, and health. The Universal Declaration can be thought of as the trunk of the human rights tree, with the UN Charter as its roots. As respect for human rights and dignity is a sine qua non for promoting and protecting human well-being, the human rights framework offers public health a more coherent, comprehensive, and practical framework for analysis and action on the societal root causes of vulnerability to HIV/AIDS than any framework inherited from traditional public health or biomedical science (ibid).

### ***Health Rights and HIV***

Conventionally, interventions in the health sector were dominated by the “Public Health approach.” With the advent of HIV, human rights approaches made forays into these interventions. It provides

both a common vocabulary for describing the commonalities that underlie the specific situations of vulnerable people around the world, and clarity about the necessary direction of health-promoting societal change (Mann et al; 1999).

When we incorporate a human rights dimension into HIV/AIDS prevention, it would mean that we identify the specific rights whose violation contributes to HIV vulnerability in our particular community or country. It might involve the right to information, the equal status of women and men in marriage or its dissolution, the right to medical care, or even the basic proposition of non-discrimination. It will also link health issues with the mobilising power of human rights and will expand the ability of people to see the connection between a ‘rights issue’ and their health.

The Universal Declaration of Human Rights, adopted by the UN General Assembly in 1948, provides societal conditions considered essential for well-being, peace, and health. The Universal Declaration can be thought of as the trunk of the human rights tree, with the UN Charter as its roots. As respect for human rights and dignity is a sine qua non for promoting and protecting human well-being, the human rights framework offers public health a more coherent, comprehensive, and practical framework for analysis and action on the societal root causes of vulnerability to HIV/AIDS than any framework inherited from traditional public health or biomedical science (ibid).

In our situation, however, a rights-based approach to address the spread of HIV is one that considers people in their contexts, i.e. an approach that considers individuals’ vulnerabilities, not just in terms of risk to HIV infection but also in terms of their vulnerability to marginalisation and the impact of marginalisation on them. A contextual understanding of vulnerabilities reveals clearly the extent to which inequalities fuel the spread of the infection. Unequal power relations, whether on the basis of gender, class, caste, or sexuality, and the existing discrimination in society are at the heart of disproportionate vulnerabilities in marginalised communities. Furthermore, in the context of HIV/AIDS, lack of power translates directly to vulnerability to infection because of the lack of knowledge and skills to adopt the appropriate measures towards reduction of harm (Ed. Grover, Kukke, and Bharadwaj; 2003).

### ***Violations***

Fear of the disease has been generated by the manner in which the magnitude of the spread and its consequences have been projected, and this has led to increased stigmatisation of affected persons and groups. Thus, stigma and discrimination associated with HIV/AIDS are among the greatest threats to successful measures aimed at prevention, alleviation of impact of the epidemic and provision of treatment, care and support. The disclosure of an individual’s HIV-positive status exacerbates prejudices and has a devastating effect on their lives. In fact, people avoid access to a public health system, as it violates their confidence, stigmatises them further, and also forces the HIV-positive persons to hide their status.

Recent research has revealed that non-consensual disclosure of a person's HIV-positive status has resulted in denial of work and denial of medical services. Disclosure of HIV-positive status has also led to gross discrimination whereby children have been expelled from school and denied their fundamental right to education.

Although the Indian government's National AIDS Prevention and Control Policy supports an approach that ensures the protection of rights as a key element in successfully dealing with HIV/AIDS, it does not have the sanction of law. Widespread violations of rights of those infected, affected and most vulnerable to the epidemic occur, most often, with the sanction of law.

### ***Manifestations of discriminatory practices in the realm of health both at the level of healthcare and ethical considerations***

#### **a) Healthcare**

In India, discrimination is particularly rampant in the healthcare sector. People Living With HIV/AIDS (PLWHAs) are often refused treatment and surgery, denied admission to hospitals or charged additionally for basic services. PLWHAs have also been subject to mandatory pre-admission testing and consequently stigmatised by having their hospital beds tagged with 'HIV-positive' or being isolated in special wards with a lower quality of care. Healthcare providers contribute to the culture of discrimination by refusing to treat and perform surgical operations, refusal to touch objects used by positive patients including utensils and bed sheets, and making HIV-positive patients wait longer than others for care (Colloquium, Lawyers Collective; 2002).

About 90 percent of people with HIV live in developing countries, and have no access to any scientifically proven treatment for the infection. Since the vast majority of people living with HIV/AIDS in India have no access to Anti Retroviral (ARV) drugs, failure to prevent the disease usually means a premature death. Anti Retroviral drugs are manufactured in India, but generic ARV drug combinations still cost about Rs. 1000 to Rs. 2000 (about U.S. \$20 to \$40) per month. The number of HIV-positive cases in India, is approximately 4 million with 10 percent of these being AIDS cases, i.e. about 400000. The cost of treatment for these patients would be around Rs. 64 crores annually. In this context, it is important to note that no government-supported programmes exist to provide anti-retroviral treatment to persons with HIV/AIDS. The recently released national AIDS policy takes the position that 'treatment options are still in the initial trial stage and are prohibitively expensive.' Government of India's Health Ministry and NACO has announced India's official position on ARV drugs that 'India cannot afford to give free anti-retroviral drugs to its HIV-positive persons' (Shiva, 2003).

According to WHO estimates, in 2002, some 6 million people in developing countries are in need of Anti Retroviral therapy and; only 230,000 have access to it, half of these people live in Brazil. In

contrast, about half a million people of the 1.6 million PLWHAs in high-income countries are on ARV therapy. In developed countries, the cost of ARVs has been borne mostly by the State and partly through insurance (ed. Grover, Kukke, and Bharadwaj, 2003). More and more people are denied access to life-saving medications due to abuse of drug patent protection, high prices, and unfair government policies. The very high cost of the anti-retroviral therapy makes it impossible for the economically disadvantaged groups to seek this treatment. Hence, greater accessibility to regular and low-cost medical care is significant in reducing the suffering of those with full-blown AIDS. However, it is not the absence of treatment that results in excessive AIDS-related morbidity and mortality, but the lack of access to existing treatments.

### **b) Confidentiality**

The maintenance of confidentiality of an individual's health status is one of the cornerstones of public health and rights-based legal responses to HIV/AIDS. Not only does the principle rest on human rights norms of autonomy and respect for privacy, but is also crucial in encouraging those most at risk to avail of HIV testing, counseling and clinical attention. India has recognised the protection of confidentiality and human rights as vital but the irony is that a patient's right to confidentiality is often seen to have been breached in both public and private hospitals.

For instance, the confidentiality of patients is not maintained when the laboratory investigations are done. The personnel demand that the patient's HIV status should be mentioned on the investigation form so that extra care could be taken while handling the patient. The patient's sero-positivity is prominently displayed in the case sheets (Ritupriya, 1999; Bhargava, 1998; Abraham et al, 2000; cited in *ibid*). The principle of confidentiality is in fact confused with sharing of the test results with a few select groups. In case of pregnant women, they are not informed about their sero-positivity and their husbands are first informed about their HIV status. Discrimination also persists in the treatment of poor illiterate individuals as compared to educated, economically better-off people with HIV infection, whose confidentiality is strictly maintained.

### **c) Consent**

Testing without the explicit consent of the individual has proved counter-productive, both as a public health strategy to control the spread of HIV and for the individual. It is thus crucial from both human rights and a public health perspective that consent be free and informed. The Charter on HIV/AIDS also states that healthcare professionals have a duty to respect the dignity and autonomy of their patients and take informed consent prior to any kind of medical intervention relating to HIV/AIDS.

The primary reason for taking consent from a person before testing and treatment is the respect for human dignity and bodily integrity as enshrined in the principle of autonomy. Nevertheless, in case

of anti-retroviral treatment informed consent helps in a sustained long-term treatment (Ed. Grover, Kukke, and Bharadwaj, 2003).

It is a well-documented fact that mandatory screening policies, which are not based on informed consent, are detrimental to HIV prevention efforts since persons most at risk of infection are likely to avoid contact with health authorities to escape identification and compulsory testing. Thus, the obligation of states to protect, both the rights of persons and public health requires the rejection of mandatory or coercive testing measures.

### ***Interrelationship between Gender relations and HIV/AIDS***

Today, the global spread of HIV/AIDS suggests the need for an analytical approach, using a human rights framework. It has been documented that in several developing countries married, monogamous women have also contracted HIV. Women in these countries know about HIV, and condoms are accessible to them. However, their risk factor is due to their inability to control their husbands' sexual behaviour or to refuse unprotected or unwanted sexual intercourse. Therefore, women's vulnerability to HIV is now recognised to be integrally connected with discrimination and unequal rights, involving property, marriage, divorce, and inheritance (Mann et al, 1999). Women infected with HIV are discriminated within their families. They are denied any kind of care and support from their spouse's families in the event of diagnosis. Social construction of gender roles lays taboos on their seeking adequate knowledge about sex and sexuality.

Therefore, the spread of the virus is greatly facilitated by the inability of many women to protect themselves because of their lower cultural and socio-economic and political status. Most of the women occupy economically dependent positions, implying lack of power, lower status, and limited influence on decisions concerning themselves and their families. Under such circumstances women cannot generally demand the use of condoms even if they know that their husbands or partners are HIV infected. Thus, the unequal power relations between men and women fuel the spread of HIV/AIDS.

Recent estimates indicate that the incidence of HIV/AIDS is increasing more rapidly among women than among men, although men had a higher infection rate when the epidemic began (Amaro, 1993; Gorna, 1996; Sherr, 1993 cited in Pallikadavath and Stones, 2003). According to the UNAIDS (December 2000) report, there were 36.1 million HIV/AIDS infected people living in the world by the end of 2000. Of these 16.4 million were women. Although statistics show that the overall number of men infected by HIV/AIDS is higher than women, they also show that so far more women have died of HIV/AIDS than men. In 1999 alone, 2.3 million women were infected with HIV compared to 2.5 million men in the same year. However, the number of women dying of AIDS in that year was 1.3 million compared to 1.2 million deaths among men. Furthermore, up to the end

of 2000, AIDS killed 9 million women compared to 8.5 million men (UNAIDS 2000; *ibid*). Thus, women living with HIV/AIDS face a dual burden, as ‘women’ and as ‘affected’ individuals. In addition to this, they have lesser access to resources and services, including treatment and care.

### ***Legal Issues***

*“Paradoxically enough, the only way in which we can deal effectively with the rapid spread of HIV/AIDS is by respecting and protecting the rights of those already exposed to it and those most at risk”* - Justice Michael Kirby (High Court of Australia).

The above quote by one of the leading experts on HIV/AIDS and law, portrays the inextricable link between human rights and HIV/AIDS. Law should be seen as an adjunct to rights. Rights, like international law, have only been partially achieved. In the context of HIV/AIDS, rights must both depend on existing law, seek to create new law, and find agencies for the universal enforcement of law. Significant human rights struggles utilising the law have been undertaken in a number of countries, and legal battles have been won on issues around the protection of privacy and guarantees against discrimination, violence, criminalisation, etc. However, in India despite the adoption of the General Comment on the Right to Health in May 2000, there is still no definition of “the highest attainable standard” or a mechanism to ensure that there is a progressive realisation of this right (Heywood and Altman; 2000).

In 1997, NACO, the central body responsible for planning and overseeing the implementation of the national HIV/AIDS programme, announced a Draft Policy for AIDS Control which supported voluntary testing, protection of confidentiality of HIV status and prohibited discrimination on the basis of HIV status in healthcare, employment and other spheres. The National AIDS Prevention and Control Policy was approved by the Cabinet in 2002, which envisages protection of human rights as an objective and not merely as a strategy for HIV prevention and control (Tandon, 2003). Formulating policies and legal strategies with a rights-based approach means using an anti-discrimination framework to propose ethical solutions to the legal and political dilemmas raised by the spread of HIV. Legal interventions are crucial, as they hold the State accountable for ensuring the creation of conditions conducive to the enjoyment and exercise of these rights.

This is because the HIV/AIDS epidemic is not about numbers. It is about people and lives. It highlights most particularly the tensions and conflicts between health, human rights, and state power. This pandemic has thus revealed critical weaknesses in laws and the health infrastructure in India, in a way that no other illness, disease or condition has done. The lack of adequate resources has pitted the rights of the patient against the rights of the doctor at very critical moments in the health delivery process, thereby increasing discrimination against persons living with HIV/AIDS.

#### IV. Marginalisation of Sexualities and the Right to Health

The marginalisation of people based on their sexualities is an impediment to the realisation of a right to health. Marginalised sexualities refer here to the sexualities of self-identified lesbian, gay, bisexual and transgendered people, as well as to all other same-sex sexual expressions. The assumption that everyone is heterosexual, and the implications of not conforming to that norm, are realities for all those who fall outside that norm, from women in small towns who are seeking to create spaces for their relationships without describing themselves as lesbians, to those who marched down the streets of Kolkata in India's first Gay Pride parade.

Human rights violations such as the invisibilisation, social disadvantaging, and criminalisation of people with same-sex preferences leads directly to the denial of a right to health in terms of lack of access and an absence of well-being. Moreover, even when healthcare is formally available, prejudices and misconceptions about sexuality can, and do, often exacerbate the cycle of discrimination. The argument is that it is only through a changed understanding of the relationship of sexuality and health that the right to health can be realised for all.

In considering the intersection between sexuality and health, 'Right to Health' must be seen as ranging from a right simply to be free from disease to mental and physical well-being, made possible only through freedom from violence, stigma and marginalisation. A disease-based notion of health is to be abandoned in an attempt to locate how the everyday experiences of sexual minorities often is of fear, guilt, shame, repression and low self-esteem, born out of homophobia. It is necessary here to question larger social concepts of sexuality in order to create a conducive and safe environment in which same-sex desiring people can claim and fully enjoy rights.

From this perspective, "Right to Health," is not only broadening the concept of "health" but also of "rights." Rights include freedom from discrimination as well as a positive, affirmative articulation. Advocacy for the right to health requires an intersectoral approach as defined by the Committee on Economic, Social and Cultural Rights. Ensuring a right to health, therefore, entails transforming wider social mores regarding sexuality in order to create the space in which individuals can define and express their sexuality free from stress and fear. Only then, can the conditions for mental and emotional well-being be fulfilled. The family is usually the first site in which a lesbian woman, a gay man, a transgendered person, or others who fall outside of the heterosexual norm will be faced with pervasive (even if unspoken) homophobia. Becoming aware of antipathy towards homosexuality and same-sex preferences, or knowing from an early age that heterosexual marriage is compulsory for them, are some of the primary factors underlying the psychological stress of marginality and invisibility. This psychological stress is compounded by other players in society, most of whom assume and reinforce heterosexuality as being the only acceptable way of being.

## *The State*

In State policies and programmes, including those relating to health, there is no acknowledgement of the existence of non-heterosexual sexualities. There are only two exceptions to this: Section 377 of the Indian Penal Code and the policies and programmes of the National AIDS Control Organisation (NACO).

In the context of same sex behavior, Section 377 strengthens the police in its widespread practice of extortion and blackmail of men who have sex with men (MSM). The special vulnerability to police harassment faced by MSMs profoundly restricts education about, and the practicing of, potentially life-saving safer sex methods. Even in more private spheres, Section 377 is also used by families to pressurise and threaten women in same-sex relationships. The very existence of section 377 therefore militates against the State's obligation to respect, protect and fulfill human rights with regard to human dignity, freedom of association, assembly and movement, privacy, non-discrimination, equality and the prohibition against torture- all of which are integral to the realisation of the Right to Health for all citizens.

The only other mention of same-sex behavior is found in the documents of the National AIDS Control Organisation (NACO), which includes MSM as a "high risk" target population. The framework of high-risk groups has been challenged, arguing that isolating certain "target populations" ends up stigmatising certain groups and leaving them outside of the healthcare system. While MSMs, find mention in the documents, none of the public awareness messages even address MSMs.

The Indian government was vocal in its support for the inclusion of the International Gay and Lesbian Human Rights Commission in the UN General Assembly Special Session on HIV/AIDS in June 2001. However, at the recent UN Human Rights Committee meeting held in Geneva (May 2003), India was one of the nations that called for the postponement till 2004, discussion of a landmark resolution on 'Human Rights and Sexual Orientation' introduced by Brazil. Activists explain this seeming contradiction as related to the fact that the context of the UNHRC meeting was not one of HIV/AIDS.

As far as criminal laws are concerned, specific attention will be focused on the main provision used to police same sex desire which is Section 377 of the Indian Penal Code. Section 377 reads:

Unnatural offences- Whoever voluntarily has carnal intercourse against the order of nature with any man, woman or animal shall be punished with imprisonment for life, or with imprisonment of either description for a term which may extend to 10 years and shall be liable to fine.'

Explanations- Penetration is sufficient to constitute the carnal intercourse necessary to the offence described in this section.

This provision does not distinguish between consensual and non-consensual sexual activity and is a clear importation of a Judeo Christian morality into the framework of the criminal law. It is important to note that the prohibition applies to certain kinds of sex, which the judiciary has interpreted as belonging to the category: 'Carnal intercourse against the order of nature.' This prohibition is neutral as to identity and applies both to heterosexuals and to homosexuals.

The hypocrisy of the State was clearly exposed earlier within the country when workers of Bharosa Trust and Naz Foundation International, NGOs working on HIV/AIDS related issues with MSMs in Lucknow, were arrested in July 2001. Lucknow's then Superintendent of Police, Mr. B.B. Bakshi, publicly stated that he would like to 'eradicate homosexuality, which is against Indian culture.' What the Lucknow incident demonstrates is the fact that the State not only fails to live up to its claims in the international arena, but actively prevents the realisation of a right to health for sexually marginalised people, in the country. The Lucknow incident shows us how necessary it is to hold the State accountable to international human rights standards related to sexuality and the right to health.

### *Access to general healthcare*

The simple access to healthcare is not adequate for the realisation of right to health in case of sexual minorities. In a homophobic social environment, in which secrecy about sexuality is the norm, proper and full attention to health needs is rendered impossible. Ensuring the right to health therefore entails entering into a process of educating healthcare professionals about issues related to diverse sexual preferences.

### *Sexuality and the mental health profession*

Several historians of sexuality have shown that while same-sex behavior and same-sex love have existed throughout history, the homosexual person is a particularly modern invention. The emergence of the homosexual as a person is closely tied to the way medical science and the law has categorised that individual, as "ill" and as a "criminal", respectively. Historically, psychology has been a critical mode through which society has sought to control the homosexual, and in the process, reinforce the "normality" of heterosexuality. The mental health profession in the current Indian context-through the equation of homosexuality with sickness, serves more as an obstruction to the right to health than a means to its realisation.

Facing familial and social pressures regarding one's sexuality can, and does, lead to an absence of mental and emotional well-being. Ideally, help would be sought, and received, from mental health professionals. However, mental health professionals are not free from the same homophobic biases and assumptions that underlie a same-sex desiring person's lack of well-being. Faced with pervasive homophobia at all levels, realising one's right to information regarding sexual choice is an unrealistic proposition. Whether we are speaking of someone wanting to explore sex reassignment surgery or of a lesbian woman convinced by family that her desires are "abnormal," the lack of reliable and accurate information, and the difficulties of obtaining it, only exacerbates the obstacles to well-being.

Experiences on helplines and in support spaces as well as fact-finding reports on lesbian suicides, for example, show the range of mental health concerns for same-sex desiring people, to include depression, suicidal feelings, and substance abuse. As several participants noted in a seminar of mental health professionals held by the lesbian and bisexual women's group, Sahayatrika (Trivandrum, November 2002), one of the pervasive points of ignorance in professional counseling is the idea that the lack of mental well-being of same-sex desiring people is directly linked to the "sickness" of that orientation itself. However, as several mental health professionals noted, it is homophobia that needs to be "fixed" in order to realise well-being, and not the orientations themselves.

A disturbing example of how mental health related problems faced by same-sex desiring people can be used against them is provided in a paper by Prof. S.D. Sharma, Professor Emeritus, Institute of Human Behaviour and Allied Sciences, Delhi. Prof. Sharma's listing of problems associated with homosexuality is as follows: 'increased suicidal tendencies, increased rate of alcohol or substance abuse, increased rate of HIV, increased problems with sexuality and sexual dysfunction, increased physical health problems and increased abnormal behavior.' His conclusion was that recognising the rights of homosexual people might result in "considerable harm." Dr. Sharma's discussion was not intended to show how the stress of marginality leads to a denial of the right to health for same-sex desiring people, but rather that homosexuality itself is a social ill, and homosexuals themselves, a liability to society. This assumption of sexual "sickness" thus stands as justification to socially, legally and medically control homosexual people. Dr. Sharma most succinctly challenges the universality of human rights in saying, in the ostensible interests of society that 'privacy cannot extend to all aspects of human life.'

For people with same-sex attraction, desires and relationships, living in a largely hostile world, the language of rights constitutes a rare space, where unashamed articulations of identity and political resistances to homophobia are possible. "Rights" as including a positive, affirmative articulation of the right to sexual and all other expression, and "health" as total emotional, mental and physical well-being, can be possible only through freedom from violence, stigma and marginalisation. Thus, simple access to healthcare is not sufficient for the realisation of a right to health for same-sex-desiring people. Access must be to services that are unbiased, sensitive and supportive of sexual difference, and particular concerns related to them. But when there is access to health services that are sensitive, the culture of pervasive homophobia needs to change in order to enable the free exchange of information necessary for an individual to realise well-being. Such perceptions and biases must be changed also to prevent human rights violations that stem from such active homophobic interventions.

## V. Sex Workers and Right to Health

Providing sexual favours in exchange for money has probably been institutionalised in the form of prostitution in every society. It has nearly always involved the prostitution of women to men, though male prostitution is not uncommon. Prostitution certainly flourished during the Victorian period of rigid sexual morality. Victorian prostitution was connected with a double standard of morality, which was much more permissive for men than for women. Defining a social category of women as prostitutes depends on several grey zones overlapped by social, cultural, economic and political systems of a particular society in a specific historical time span.

Prostitution is often said to be the oldest profession. Indian history is unique in acknowledging prostitution and the State's responsibility to protect the rights of prostitute women. Kautilya, in his *Arthashastra*, has a chapter titled "The Chief Controller of Entertainers (Courtesans, Brothels, Prostitutes and other Entertainers) Responsibilities." He makes the distinction between prostitution and trafficking, and emphasises the absolute necessity for the willingness and consent of the prostitute to engage in a sexual relationship (S. Nataraj, 2002). Over time this courtesan tradition was replaced in many places in India by the 'Devadasi' system, which rendered the woman as public property and removed her right to independent choice.

That the exchange of sexual services for money or goods has existed in every society throughout history is indisputable. However, the respect accorded to those who provide these services has varied widely over time and space. The ethical and political ideas about sexuality and sexual practices are socially constructed and historically and contextually specific. At the present juncture, ideologies about sexuality are deeply entrenched within structures of patriarchy and largely misogynist mores. The state and social structures only acknowledge a limited and narrow definition of sexuality, ignoring its many alternate expressions, experiences and manifestations. Our societal norms and regulations allow for sexual expression only between men and women within the strict boundaries of marital relations within the institution of family. Sex is seen primarily and almost exclusively, as an instrument of reproduction, negating all aspects of pleasure and desire intrinsic to it. The contemporary stigma attached to sex work operates through dominant ideas about gender, class, caste, race and most importantly, 'respectability' that strategically distinguishes between the morally 'corrupt' and the morally 'pure.' This distinction has relied on class parameters, identifying middle class norms of sexuality as 'respectable' and essentially enabling the criminalisation of poor and working class communities (Grover *et al*, 2003).

### *Need to address the rights of Sex Workers*

Creating a framework for a discussion of the rights of women in sex work is not easy. This is particularly true in the Indian context where an overwhelmingly large number of women have been trafficked due to the prevailing social, psychological, and economic conditions in our country rather than by organised

criminal networks. In addition to this, the existing laws are ambiguous enough to allow the abuse of women by state agencies. This particular group is socially marginalised in all societies across the globe, subjected to sexual and economic exploitation, and are denied basic human rights like healthcare, education for their children, voting rights etc., which further worsens their position.

The terms ‘sex work’ and ‘sex worker’ have been coined by the growing sex workers’ rights movement in order to emphasise that commercial sex is an income generating activity or form of employment for women and men. This has been done in response to terms like ‘prostitute’, which are seen to connote stigmatised social and psychological characteristics of a class of women (Grover, et al, 2003). It is used as a descriptive term denoting a homogenised category, usually of women, who pose threats to public health, sexual morality, social stability and civic order. In this context it is important to quote a few lines from the ‘Sex Workers’ Manifesto - “We believe that like any other occupation sex work too is an occupation, and not a moral condition. But the word ‘prostitute’ is rarely used to refer to an occupational group of women who earn their livelihood through providing sexual services. It is deployed as a descriptive term denoting a homogenised category, usually of women, who pose threats to public health, sexual morality, social stability and civic order. Within this discursive boundary we systematically find ourselves to be targets of moralising impulses of dominant social groups through missions of cleansing and sanitising both materially and symbolically.”

It is critical to place sex work in its economic context and employ a labour perspective when analysing its position in larger human rights debates at local, national and international levels. This vulnerability of sex workers to exploitation in the workplace and to violence and harassment by clients, agents, police, local mafia and the public is aggravated by the lack of provisions to protect their rights (Grover et al; 2003) Thus, protecting their rights is a difficult challenge. These vulnerabilities are accompanied with obvious consequences for the health and well-being of sex-workers. At this juncture, it is imperative to put forth that the HIV/AIDS epidemic has served to further stigmatise women in sex work. Already pushed to the margins of society, the sex workers now have to bear the additional burden of being classified as high risk and considered core transmitters of HIV infection (Misra et al; 2000). In fact, sex work also involves occupational hazards like unwanted pregnancy, painful abortions and risk of sexually transmitted diseases. However, it is in the context of HIV/AIDS, that the need for worker protection, particularly occupational health and safety provisions, are considered especially important, as the lack of information, materials or negotiating skills increases the sex workers’ vulnerability to contracting HIV.

However, there has been an obvious manifestation that the moral, social and legal censure that sex workers endure has increased dramatically with the advent of the HIV epidemic. This is primarily due to widespread belief that sex workers are ‘vectors’ of infection, serving as a ‘pool’ of infection that is propelling the epidemic into the general population. Prevalence rates among sex workers in

urban areas have shown a rising trend. In Vellore, Tamil Nadu, HIV prevalence among sex workers rose from 2 percent in 1986 to 58 percent in 1999, while in Mumbai, the “AIDS Capital” of the country, prevalence of HIV infection among sex workers reached 71 percent in 1997 (Report on the Global HIV/AIDS epidemic, UNAIDS; cited in Grover et al; 2003). To reduce the sex workers primarily to vectors of disease is to obscure their own vulnerability to HIV. Sex workers face discrimination and exploitation in matters of healthcare, i.e. various measures that directly violate the rights of sex workers have been implemented in order to control the spread of the epidemic. One such measure is mandatory HIV testing for sex workers. Mandatory health examinations drive vulnerable populations underground and erode their ability to access information and health services, i.e. voluntary counseling and testing, treatment and support. This strategy absolves clients of all responsibility for practicing safer sex, making sex workers vulnerable to coercive and unsafe sexual practices (ibid).

For the general population, healthcare professionals recommend HIV test whenever recurrent fever, symptoms of tuberculosis, diarrhea or an STI are present. For sex workers, however, HIV tests are recommended even for a single episode of illness, making them feel further stigmatised and marginalised. In a women’s hospital frequented by sex workers in Mumbai, health workers take a blood sample from every woman seeking treatment without explaining to her the purpose and nature of the test, which can be seen as a violation of her rights to information, to privacy, and to security of person. There is no post-test counseling, and the manner of revealing test results lacks discretion (quoted is S. Bharat; cited in Misra et al; 2000).

However, it is important to note that the issues of women in sex work and their problems, have come into focus only after they received immense attention in the context of AIDS control and public policy. But it is starkly obvious that AIDS is not the only vital issue in their lives. There in fact, are a number of complex issues influencing the lives of sex workers. The important issues are indeed the degrading living conditions and the overall exploitation that the women in sex work are subject to. These issues include absolute inhuman, degrading conditions of living and work, little or no access to healthcare, no citizenship rights like having a ration card, no voting rights, heavy economic indebtedness, economic and sexual

Almost all segments of the Indian population can legitimately complain about the failure of the State to protect their rights, although some, such as sex workers, appear to be particularly badly off in this regard. Despite the existence of laws that seek to prevent human rights violations, the poor implementation of these laws in India has meant that several vulnerable groups have been unable to fully enjoy the gains in well-being realised by other groups, whether in the form of better education, health, or other indicators of freedom and happiness. In this context, sex workers stand out as being particularly vulnerable. Many sex workers enter the profession when they are minors, often without their consent, and thereby become vulnerable to sexual violence and economic exploitation. To substantiate our argument, it is imperative to take note of a survey conducted among 300 brothel sex workers in Sangli district, which showed that nearly half had entered the profession at an age of 16 years or less and about one-tenth had entered at 13 years or less (quoted from A. Mahal and M. Seshu; ibid, 2000).

harassment by the 'gharwalis', pimps, local goons and the police, meager savings and no alternate shelter, no safe spaces for children, and an overwhelming fear of entering the public spaces on the account of discrimination, stigma and hostility. In fact, all these factors are responsible for increasing the sex worker's vulnerability to AIDS and exacerbating its impact on those who have already been infected. In a manner of speaking, it is imperative for any awareness or prevention programme to address these complex problems, and locate the question of AIDS in the context of these conditions, which are crucial in determining women's vulnerability to AIDS and its impact.

Sex workers also face discrimination and exploitation in terms of earnings for their services, and obtaining financial credit. Sex workers (especially minors) find their earnings from sex work appropriated by brothel owners and traffickers, and what is left over is further reduced as a result of the extremely high rates of interest charged by money lenders. According to one report, the women in some of Mumbai's brothels are forced to give over half their earnings to the brothel owners; and estimates based on a study in Sangli are somewhat lower, at about 25 percent. The study in Sangli also found that in some cases, the interest rate charged to sex workers could exceed 100 percent per month<sup>63</sup> (Mahal and Seshu; 2000). With little access to banks and other financial institutions - as a result of lack of education, lack of information about available options, and the social stigma associated with sex work, these constraints ensure that a large number of sex workers find it almost impossible to get out of indebtedness during their lives. Literacy levels among sex workers were less than 12 percent in Sangli, well below even that among rural Indian women (Mahal and Seshu; *ibid*). A direct consequence of the factors discussed above is poor health among sex workers.

### ***Health consequences of the violation of the rights of Sex Workers***

The sex workers in India are subject to frequent harassment and detention by the police, even though, according to the Immoral Trafficking and Prostitution Act (ITPA) of 1986, sex work is in itself not illegal if it is practiced privately and independently. In an intensive study on the implementation of the laws of sex work, D'Cunha found that between 1980 and 1987, more than 900 women in sex work were arrested in Mumbai alone (quoted from D'Cunha, cited in *ibid*). These women were later released in return for money.

To understand the nature and extent of police violence against women in sex work, a study (Mahal and Seshu; *ibid*) conducted with 172 women from 13 districts of Tamil Nadu, in October 2000 reflects that nearly 70 percent of sex workers reported that they had been beaten with lathis and logs of wood as well as kicked by booted police officers. Some had their hand and legs broken and their sex-organs mutilated. Others repeated incidents of slapping, twisting of hands and ears, pulling of hair, spitting on the face etc., leading to long term effects on their physical, mental and social well-being.

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63 Credit interest rate is high for all women in Chit funds.

Violence by law enforcers makes sex workers even more vulnerable to sexually transmitted infections and HIV. The ITPA also provides mandatory medical examination of sex workers to ascertain the presence of STIs. The reason for testing for venereal diseases is not clarified in the statute and the provision is also used to conduct mandatory testing for HIV/AIDS. Additional human rights violations include denial of housing, the right to self-worth and dignity and the right to bear and rear children (The definition of “neglected juvenile” in the Juvenile Justice Act, 1986, includes children of sex workers), all of these adding to their vulnerability (ibid). Therefore, there is an urgent need to amend the laws, in order to provide a secure and dignified life for sex workers in India.

## Chapter 3

# Right to Health in the Human Rights Mechanism

The problem of health and access to healthcare is colossal and with the evolution of newer policies, often dictated by the global market and international donor agencies, the situation can only worsen day by day. The government has already begun a process of privatisation in all sectors, including health, thereby abdicating all its responsibilities for those sectors. Important public services such as PDS are being discontinued. Subsidies are being cut from crucial sectors that were at one point protected by the State so that such goods or services could be affordable to a larger number of people, particularly the poor and middle classes. A definite model of development is being pursued that will benefit only the upper middle and rich classes who have the money power to consume and generate profits for national and transnational companies. The poor and marginalised have no place in that paradigm.

But, that does not mean the poor will cease to exist, neither will their deprivation or assertion. One of the ways they can assert themselves is by dealing with issues from the human rights perspective because in the human rights perspective, an individual or a community is at the centre, around which all arguments and interventions revolve.

### Health as a human right

Once a country agrees to become a signatory to any of the human rights treaties, it is legally bound to respect, protect, promote and fulfill all the rights enshrined in the treaties it ratifies. Many of the treaties have a provision for monitoring. In ratifying, a country also accepts to be monitored if and when such a need arises. Some of the treaties, however, may not have coercive powers, but the rights enshrined in them can be used to form legal arguments, reinterpret existing laws or even change them. India has ratified most of the treaties and hence is legally bound by these to fulfill the obligations that these treaties vest on the country.

#### What are Human Rights?

Human Rights are legally guaranteed by human rights law, protecting individuals and groups against actions that interfere with fundamental freedoms and human dignity. They encompass what are known as civil, cultural, economic, political and social rights. Human rights are principally concerned with the relationship between the individual and the state. Governmental obligations with regard to human rights broadly fall under the principles of respect, protect and fulfill. In turn, the obligation to fulfill contains obligations to facilitate, provide and promote.

Health is recognised as a basic human right by several human rights instruments, treaties, declarations and covenants in the international human rights mechanism. The constitution of the WHO in 1946

defined the right to health as *the highest attainable standard of health*. Article 25 (1) of the Universal Declaration of Human Rights (1948) affirms that *everyone has a right to a standard of living adequate for the health of himself and his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control*.

In 1966, the International Covenant on Economic, Social and Cultural Rights (ICESCR) provided a more comprehensive Article on the right to health in the international human rights law. According to the Article 12 (1) of the ICESCR, *States Parties recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Further, Article 12 (2) of the Covenant enumerates, by way of illustration, a number of steps to be taken by the States Parties to achieve the full realisation of this right.

The right to health was further reiterated in 1978 in what is known as the *Health for All by 2000 AD* document, or the Alma Ata Declaration, which highlighted the following three basic points:

- i) Health is a fundamental right and its realisation requires the action of many other social and economic sectors. The current gross inequality in health status is politically, socially and economically unacceptable.
- ii) People have a right and duty to participate individually and collectively in the planning and implementation of their healthcare.
- iii) Primary Health Care includes in the least, health education, promotion of food supply and proper nutrition, an adequate supply of safe water and basic sanitation, maternal and child healthcare, including family planning, immunisation against the major infectious diseases, prevention and control of locally endemic diseases, appropriate treatment of common diseases and injuries and provision of essential drugs.

Additionally, the right to health is recognised, *inter alia*, in the Convention on the Elimination of Racial Discrimination (CERD) of 1963, the Convention on the Elimination of all forms of Discrimination against Women (CEDAW) of 1979 and in the Child Rights Convention (CRC) of 1989. Several regional human rights instruments also recognise the right to health, such as the European Social Charter of 1961 as revised, the African Charter on Human and People's Rights of 1981, and the Additional Protocol to the American

All human rights are universal, indivisible, interdependent, and interrelated. The international community must treat human rights globally in a fair and equal manner, on the same footing, and with the same emphasis. While the significance of national and regional particularities and various historical, cultural and religious backgrounds must be borne in mind, it is the duty of States, regardless of their political, economic and cultural systems, to promote and protect all human rights and fundamental freedoms. (Vienna Declaration and Programme of Action adopted at the World Conference on Human Rights, Vienna, 14-25 June 1993).

Convention on Human Rights in the area of Economic, Social and Cultural Rights of 1988 (the protocol entered into force in 1999). Similarly, the right to health has been proclaimed by the Commission on Human Rights and further elaborated in the Vienna Declaration and Programme of Action of 1993, the International Conference on Population and Development Programme of Action (The ICPD Programme of Action, 1994) and The Fourth World Conference on Women - Platform for Action (The FWCW Platform, 1995).

In spite of providing a comprehensive conceptual framework of right to health, for many years, the normative definition of this right in the ICESCR was too broad. Rights activists the world over criticised its normative content as vague and based on the traditional notion of health as “goods to be provided.” But with constant pressure from activists, globally, and especially from Latin America, the Committee on ESC Rights significantly clarified and expounded on the normative content through a General Comment (CESCR General Comment 14: The Right to Highest Attainable Standard of Health) issued in 2000.

The following are some key elements of General Comment 14:

The right to health in all its forms and at all levels contains the following interrelated and essential elements, the precise application of which will depend on the conditions prevailing in a particular State Party:

- (a) *Availability*: Functioning public health and healthcare facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State Party. The precise nature of the facilities, goods and services will vary depending on numerous factors, including the State Party’s developmental level. They will include, however, the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action Programme on Essential Drugs.
- (b) *Accessibility*: Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State Party. Accessibility has four overlapping dimensions:

*Non-discrimination*: Health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalised sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.

*Physical accessibility*: Health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalised groups, such as ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons

with disabilities and persons with HIV/AIDS. Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities.

Economic accessibility (affordability): Health facilities, goods and services must be affordable for all. Payment for healthcare services, as well as services related to the underlying determinants of health, has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.

Information accessibility: Accessibility includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality.

- (c) *Acceptability*: All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.
- (d) *Quality*: As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires, inter alia, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.

Universal access to good quality healthcare equitably is the key element at the core of this understanding of right to health and healthcare. To make this possible the States Parties are obligated to respect, protect and fulfill the above in a progressive manner. The right to health, like all human rights, imposes three types or levels of obligations on States Parties - the obligations to *respect*, *protect* and *fulfill*. In turn, the obligation to *fulfill* contains obligations to facilitate, provide and promote.

The obligation to *respect* requires States to refrain from interfering directly or indirectly with the enjoyment of the right to health. The obligation to *protect* requires States to take measures that prevent third parties from interfering with Article 12 guarantees. Finally, the obligation to *fulfill* requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realisation of the right to health (Ibid).

The Alma-Ata Declaration, proclaims that the existing gross inequality in the health status of the people, particularly between developed and developing countries, as well as within countries, is

politically, socially and economically unacceptable and is, therefore, of common concern to all countries. States Parties have a core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights enunciated in the Covenant, including essential primary health care. Read in conjunction with more contemporary instruments, such as the Programme of Action of the International Conference on Population and Development, the Alma-Ata Declaration provides compelling guidance on the core obligations arising from Article 12. These core obligations are:

- (a) To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalised groups.
- (b) To ensure access to the minimum essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone.
- (c) To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water.
- (d) To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs.
- (e) To ensure equitable distribution of all health facilities, goods and services.
- (f) To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalised groups.

The Committee also confirms that the following are obligations of comparable priority:

- (a) To ensure reproductive, maternal (pre-natal as well as post-natal) and child healthcare.
- (b) To provide immunisation against the major infectious diseases occurring in the community.
- (c) To take measures to prevent, treat and control epidemic and endemic diseases.
- (d) To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them.
- (e) To provide appropriate training for health personnel, including education on health and human rights.<sup>64</sup>

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<sup>64</sup> Committee on Economic, Social and Cultural Rights, Twenty-second session, 25 April-12 May 2000, Source: *Operationalising Right to Health*, Ravi Duggal, CEHAT.

## Indivisibility and complementarity of rights

All rights are interdependent and complementary to one another and the realisation of one set of rights requires the fulfillment of all the interconnected rights. If we take the example of the right to health, the realisation of this right is dependent on a range of underlying determinants, such as food, education, environment, housing, working conditions, poverty, and so on. Unless all the problems in these determinants are also addressed, it is not possible to ensure the right to health. So, when citizens demand the fulfillment of the right to health, the process also demands all the determinant factors to be addressed and fulfilled. Similarly, when the State violates one specific right, its interconnectedness to various other rights results in a chain of violations, each of which individually stands as a right, and has its own set of norms and obligations on the states that have ratified them.

The Right to Health is indivisible and interdependent on the following rights:<sup>65</sup>

### 1. **Right to Food**

In Article 24(2) (c) of the CRC and Article 12(2) of CEDAW, the right to food is considered to be part of the right to health of both children and women. According to CESCR's General Comment 12, national strategies on the right to food need to be developed in coordination with the development of health measures, among others.

### 2. **Right to a Healthy Environment**

Article 12(2)(b) of the ICESCR specifies the environment as one of the areas for state intervention in the realisation of the right to health. This provision has traditionally been interpreted as relating simply to occupational health, but in State reporting to the CESCR, it is increasingly being considered as relating to all environmental issues that affect human health. Primary healthcare strategies include access to clean drinking water and sewage services, and preventive health programmes should include control over human activities that may expose people to environmental hazards detrimental to their health.

### 3. **Right to Adequate Housing**

General Comment 4 on the right to adequate housing links the availability of basic services, such as drinking water, housing conditions that protect individuals from health hazards, the availability of healthcare services and freedom from health related environmental risks as core elements of the right. WHO has identified housing conditions as the environmental factor having the most relevant impact on the prevalence of epidemiological diseases.

### 4. **Right to Education**

Realisation of specific core elements of the right to health has a prerequisite fulfillment of a

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65 *Circle of Rights: Economic, Social and Cultural Rights - A Training Resource*, IHRIP & Forum Asia, 2000.

basic right to education for all. In addressing the child's right to health, Article 24(2)(e) of CRC links to the right to education and thereby access to basic knowledge about children's health. Primary healthcare, in general, includes a need for education on prevailing health problems and methods for preventing and controlling them.

#### **5. Right to Work and Rights At Work**

The right to work is closely related to the right to adequate living conditions. The latter in turn is essential to health. In addition, ICESCR Article 12(2)(c) identifies prevention, treatment and control of occupational diseases as part of the scope of the right to health. Article 12(2)(b) refers to industrial hygiene which makes it necessary to adopt measures for the prevention and control of hazardous conditions in the work place. In addition, there are numerous ILO conventions that address occupational health.

#### **6. Right to Life**

While the right to life is usually considered to offer protection against killing by state actors, in its General Comment 6, the Human Rights Committee considers it desirable for states to adopt all possible measures to reduce infant mortality and to foster life expectancy, especially by adopting measures to eliminate malnutrition and epidemics. In addition, several national constitutions mention the right to health as an essential component of the right to life.

#### **7. Right to Information**

Access to adequate information is essential for appropriate healthcare. Information related to health policies and resources is necessary to allow for monitoring public policies related to health and effective social participation in health-related policy processes.

#### **8. Physical Integrity**

Apart from prohibiting the imposition of acts of torture or ill treatment, Article 7 of the International Covenant on Civil and Political Rights (ICCPR) explicitly prohibits medical or scientific experimentation on human beings without a full understanding of the extent of the experiment and prior consent. The UN Principles of Medical Ethics relevant to the Role of Health Personnel establish a series of guidelines to guarantee that health personnel will protect prisoners and detainees against any form of ill- treatment.

### **Health in the Indian Constitution**

The Indian Constitution does not specifically recognise health as a fundamental right. However, Article 21 of the Indian Constitution recognises the right to life as a fundamental right. The right to life has been used in various legal arguments and judgments as a basis for preventing avoidable disease-producing conditions and to protect health and life. The Directive Principles of the Indian

Constitution, however, include Article 47, which specifies the duty of the State in this regard.

It is interesting to note that 56 years ago, independent India's first charter on health, the Bhore Committee report of 1946, demonstrated a genuine commitment to universal healthcare. It began with the opening statement: *No citizen should be denied adequate quality of healthcare merely because of his or her inability to pay for it.* This charter had many of the guidelines and recommendations that the ICESCR General Comment 14 issued in 2000. Some of the key recommendations of the Bhore Committee report were:

- Integration of preventive and curative health services at all administrative levels.
- Development of Primary Health Centres in two stages:

One Primary Health Centre for a population of 40,000 and secondary health centre to serve as a supervisory coordinating and referral institution. A long-term programme of setting up primary health units with 75-bed hospitals for every 10,000 and 20,000 population and secondary units with 650-bed hospitals.

- Major changes in medical education: 3 months training in preventive and social medicine to prepare social physicians. Formation of Village Health Committees.
- Formation of the District Health Board for each district.
- Laying emphasis on preventive health services.
- Inter-sectoral approach to health service development.

Though these recommendations did not strictly reflect the rights perspective, it was the first time a comprehensive proposal for the development of a national programme for health services for the country was put forward. Unfortunately, these recommendations are yet to be implemented comprehensively.

1. The '**Right to Life**' (Article 21) enshrined in the constitution makes a case for provision of emergency medical care, and protection from all threats to life.

**Article 21: Protection of Life and Personal Liberty**

No person shall be deprived of his life or personal liberty except according to procedure established by law.

2. The **Directive Principles** regarding Nutrition, Standard of Living and Health (Article 47).

**Article 47: Duty of the State to raise the level of nutrition and the standard of living and to improve public health**

The state shall regard the raising of the level of nutrition and the standard of living of its people and the improvement of public health as among its primary duties and, in particular, the state shall endeavor to bring about prohibition of the consumption, except for medicinal purposes, of intoxicating drinks and of drugs, which are injurious to health.

The **93rd amendment** in the Constitution accepting education as a Fundamental right has strengthened the case of basic social services to be accepted as people's right.

## Chapter 4

# Violations of the Right to Health

While it is important to analyse and critique the inadequacy and lacunae in the physical aspects of health and healthcare, it is also necessary to look into some specific case studies that raise larger issues concerning the right to health. These violations may or may not be strictly related to the service delivery aspect of healthcare, but maybe actions by the State and public health institutions that are in direct conflict with the rights of individuals and communities. In general terms such invasive actions could be overlooked as isolated incidents or at best criticised as callousness of the authorities. Also, due to the interconnection of rights, violation of any one right actually ends up violating a series of rights in the process. However, seen from the rights perspective, these could turn out to be serious violations of human rights that the State is legally obligated to respect, protect, and fulfill.

### I. Violation of Medical Ethics in Research

#### Letter to the Editor citing cases of violation of rights in Human-trials

February 4, 2004  
Dr. Daniel R. Mishell, Jr. M.D.  
Editor, Contraception  
Department of Obstetrics and Gynecology  
University of Southern California School of Medicine  
Women's & Children's Hospital  
Room L-1009,  
1240 North Mission Road, Los Angeles  
California USA 90033

**Reference:** Response to Article by Bairagy and Mullick, *Contraception*, 69: 47-49, 2004

Dear Dr. Mishell:

We were astonished to read the article "Use of erythromycin for non-surgical female sterilisation" (*Contraception*, 69: 47-49, 2004) published in your journal. Our astonishment stems from the fact that we assume, perhaps naively, that scientific journals publish results of clinical trials that adhere to well established guidelines for conducting research on human subjects, such as the World Medical Association Declaration of Helsinki, (1) or the CIOMS guidelines (2).

Major questions emerge about the publication of this article. The paper asserts that women signed consent forms that state, "in the opinion of the investigator the method was safe but its efficacy was unknown." Would NIH or any other Research Ethics Board accept the signing of such a document as evidence of obtaining Informed Consent? Did *Contraception* and its reviewers ask the authors to describe the steps they took to get a clinical trial approved? Are you aware that the Indian Council of Medical Research is the body empowered to approve clinical trials in India? Ethical permission cannot be granted by a committee of an NGO, as has happened in this case. Did the reviewers find out whether the executive committee of the

Indian Rural Medical Association had a research protocol that was approved for a phase II clinical trial? Why did the authors change the experimental design and increase the number from 100 to 690 for “reasons of compassion” when the data had not been analysed to prove the efficacy rate? The lack of satisfactory answers to such questions raises very serious doubts about the scientific credentials of your journal and its reviewers. The laws in India are clear: research on human subjects can only be carried out - after going through mandated laboratory stages - with the approval of the Drug Controller of India. The laws are equally clear that a drug approved for one clinical purpose would still require the same procedures as a new drug if it is to be utilised for another therapeutic purpose. In short, if erythromycin or tetracycline is to be tested as agents for female sterilisation, they will need prior approval from the Drug Controller of India (3).

The authors of the present study had earlier conducted illegal trials with quinacrine for similar purposes (4).

The Supreme Court of India not only banned these trials in a landmark judgment in 1998, but also made this punishable by fine and imprisonment (5). That, they have not been punished has apparently emboldened them to carry out the current study.

In this instance, the death of the senior author (March 2003), prior to submission of the article in April 2003, raises questions about the scientific responsibility of the corresponding author, Dr. Steven Mumford who has, however, chosen not to be identified as the author of the paper. In light of the vested interest in quinacrine non-surgical sterilisation (6), we wonder if the trials reported in Contraception are intended to derail a proper scientific investigation of erythromycin, which Family Health International is pursuing (7).

Your journal owes its community of readers an apology for publishing - and thus lending credibility - to an illegal study. The peer reviewers should have paid attention to the prior criminal antecedents of the authors and their violation of universal ethical norms evident in the study. We are sending copies of this letter to the Medical Council of India, the Government of West Bengal and the Drug Controller of West Bengal, calling for exemplary punitive action against the authors of the study. Indeed, they have been referred to as “repeat offenders” in a leading national newspaper (8).

Sincerely,

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### ***Research on cervical dysplasia***

The Institute of Cytology and Preventive Oncology (ICPO), a body under the Indian Council of Medical Research (ICMR) carried out a study of the rates of progression of uterine cervical dysplasia to malignancy. The relevance of the study lies in the fact that cervical cancer is the most common cancer among Indian women and, the identification of relevant risk factors and the detection and management of the prevention of the cancer is an imperative need. In order to understand the issue,

the study was initiated in 1976 and continued till 1988. The project explored how growth at times turns malignant or disappears without treatment.

The study was done in 6 major hospitals in Delhi. In the initial stages trained medical people collected smears for cytological assessment. Coloscopic examinations were started only in 1982. As part of the study the ICPO team selected 1158 women between 1976 and 1988 with varying degrees of cervical dysplasias for long-term follow-up. The women were from nearby villages of Delhi. Most of them were neo-literates, from among the lowest economic backgrounds. The strategy was simple. The research team got in touch with the anganwadi teachers who were asked to motivate women for the study. The anganwadi teacher was paid for every case she brought to them.

Apart from the motivators, the women were informed that they were part of the research on cervical dysplasia. They were told that cancer was a “jaan leva bimaari” (lethal disease) and that any woman could have cervical cancer and that the test would help them. Initially women were hesitant to participate, but the anganwadi teachers convinced them to do so. The teachers themselves were also part of the test. After the initial pap test, a few women were selected and they were examined regularly without any explanation, information or treatment options. After the initial pap test, the women were taken to the hospital, but not for any treatment.<sup>66</sup>

### ***M4N clinical trials***

The anarchy in medical research in the country is typified in these examples. This pertains to a clinical trial conducted on human subjects in the Regional Cancer Centre (RCC) in Kerala, with an experimental drug in advanced oral and cervical malignancies. The trials were conducted in collaboration with the Johns Hopkins University in the US. The drug used, M4N, is an active principle of ‘*chaparral tea*’ made from leaves of the creosote bush, a common American desert plant, although chaparral tea has been known to have toxic effect on the liver. While the trial was conducted in 1999 and 2000, application for permission to conduct the trial was forwarded to the Drug Controller of India only in February 2001! Further the Ministry of Health and Welfare states that the RCC was granted permission to import M4N from Johns Hopkins only in February 2, 2001. Apart from these procedural problems, it now appears that the trials ignored basic norms regarding informed consent. Further, a preliminary enquiry indicates those subjects enrolled in the trial were given the experimental drug in preference to establish treatment regimes, a clear violation of the Declaration of Helsinki on research on human subjects. The trials had not been approved or reviewed by any of Johns Hopkins Institutional review boards concerned with the protection of human subjects, in spite of the Center’s claims that the permission for the trials was granted on the basis of ‘pre-clinical and other relevant data.’<sup>67</sup>

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66 *Where Women are Guinea Pigs*, N.B. Sarojini.

67 Research on Hire, Amit Sen Gupta, *Issue in Medical Ethics*, IX (4), October-December 2001).

## ***Injectable contraceptives***

It is well known that injectable contraceptives have been in the eye of storm for a long time. For several decades, the government has been trying to introduce them in the Family Planning programme. Women's groups have been consistently campaigning against the introduction of these untried, untested hormonal injectables and implants, as they are known to have severe adverse impacts on women's health. The trials on long-acting hormonal contraceptives like Net En, Depo-Provera and Norplant were conducted without observing the ethical requirements such as informed consent, follow-up and counseling. However, the strong resistances from the women's groups have over the years made the government completely non-transparent about their plans and actions surrounding these drugs.<sup>68</sup>

In 1983 and 1984, the Indian Council of Medical Research (ICMR) initiated the Phase IV (Programme Introduction) Study in various urban and rural centers to assess the acceptability of Net En in order to introduce injectable contraceptives in the National Family Welfare Programme.

Patancheru, near Hyderabad in the state of Andhra Pradesh, was one of the centers where this study was being conducted. Members of the Stree Shakti Sanghatana, a Hyderabad based women's organisation, came to know about the trial and visited the PHC at Patancheru on April 1, 1985. A camp had been organised to introduce the injectable Net En. This PHC was selected by the Osmania Medical College for the Phase IV trial.

The activists soon learnt from the women who had been assembled at the PHC that they knew nothing about the contraceptive that was being administered to them. Neither did they have any knowledge about the trials. The only information they had been given was: "*Injection le lo, Bachcha nahin hoga*" (Take this injection, you won't get pregnant). The women were from the poorest class.

When confronted, the para-medics said that they were assigned the task of procuring 20 recruits for the trial from the nearby areas. They confessed that they had not informed the women. They were afraid that no one would have volunteered if they had told the women that they were subjects of an experiment, or that the contraceptive could cause possible side effects.

Ethically speaking, any such trial or research which uses human beings as subjects for medical experiment or assessment requires informing the participants of each and every detail of the study and

### **Informed Consent stated by the Helsinki Declaration on Human Experimentation**

In any research on human beings, each potential subject must be adequately informed of the aims, methods, anticipated benefits and potential hazards of the study and the discomfort it may entail. He or she should be informed that he or she is at liberty to abstain from participation in the study and that he or she is free to withdraw his or her consent to participation at any time. The doctor should then obtain the subject's freely given informed consent preferably in writing.

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68 *Campaign against Injectables*, Sarojini N.B, CDC publication.

all the possible impacts of the drug on the body, however remote they may be. Moreover, it is a norm to have the consent of the participants in writing — a process known as ‘informed consent.’

This case demonstrates outright breach of the ethical norms of informed consent by a state agency, which is a clear violation of Medical Ethics and transgression of the Helsinki Declaration on Human Experimentation to which India is a signatory. It not only violates the right to health in terms of the state’s obligation to respect and protect; it also violates the right to information and a series of rights concerning women and health. Unfortunately, such violations are taking place every day and people rarely come to know about them.<sup>69</sup>

### **CEDAW Article 12**

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of healthcare in order to ensure, on a basis of equality of men and women, access to healthcare services, including those related to family planning.
2. Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

### **Recommendations of the World Medical Association, Declaration of Helsinki**

1. Recommendation on Scientific Basis for Human Trial: Biomedical research involving human subjects must conform to generally accepted scientific principles and should be based on adequately performed laboratory and animal experimentation and a thorough knowledge of the scientific literature (Basic principles:Paragraph 1).
2. Recommendation on Approval of Research Protocol: The design and performance of each experimental procedure involving human subjects should be clearly formulated in an experimental protocol which should be transmitted for consideration, comment and guidance to specially appointed committees.
3. Guidelines for Right to Compensation: Research subjects who suffer physical injury as a result of participation are entitled to such financial or other assistance as would compensate them equitably for any temporary or permanent impairment or disability. The right to compensation may not be waived (Guideline 13: Right of subjects to compensation).
4. Guidelines for standards of clinical trials: An external sponsoring agency should submit the research protocol to ethical and scientific review according to the standards of the country of the sponsoring agency, and the ethical standards applied should be no less exacting than they would be in case of research carried out in that country (Guideline 15: Obligations of sponsoring and host countries).<sup>70</sup>

## **II. Policies, Targets and Violations**

### ***Coercion to meet targets***

In Lingareddipalli village of Ouzel mandal of Gudur revenue division, people having assigned land, which they were cultivating, were obstructed by revenue officials from harvesting their crop. They

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<sup>69</sup> *Enough is Enough*, Saheli publication, Saheli Newsletters.

<sup>70</sup> *International Ethical Guidelines for Biomedical Research Involving Human Subjects* prepared by Council for International Organisations of Medical Sciences (CIOMS) with World Health Organisation (WHO), 1993.

were told that unless they underwent the family planning operation they would not be permitted to harvest. Flags were placed on fields of persons refusing to undergo sterilisation, and the revenue officials threatened to lodge a police complaint and move the court if anybody defied their orders. With the support of a local voluntary organisation, the people went ahead and harvested their crop. This led to a threat from the Mandal Revenue Officer (MRO) that he will report the organisation's activities as "anti-government" to the District Collector. Further, about nine hundred families from forty villages in the same area were being denied access to the PDS, house site pattas and government loans because they were refusing to undergo laparoscopic sterilisation.

In Ananthapur district, when it was found that the health department was behind the scheduled target of FP operation, the local revenue and Panchayati Raj departments were also pulled in to help achieve targets. Monthly targets were fixed for each MRO and Mandal Development Officer (MDO). These responsibilities were in turn entrusted to the Village Administrative Officers, Village Development Officers and school teachers. In a bid to attract a larger number of women, these officers unofficially announced incentives like land pattas, house sites, bank loans, ration cards etc. Statistics show significant increase in the target achievement figures as compared to the original target, that is 2417 sterilisations per month (Eenadu, 7 February, 1994).

MROs and MDOs were given awards for reaching the targets on Republic Day. However, promised incentives (which in principle is wrong) were not given to the women. Further women in the villages felt very threatened that land given to them by the government would be taken back if they refused to undergo FP operations. Each DWCRA group that was formed was also asked to "give a case" if they wanted a programme sanctioned.<sup>71</sup>

There are many such examples of violations targeting women under population policies. The UP Population Policy has re-introduced method specific contraceptive targets to the extent of 10 lakh sterilisations and 30 lakh spacing method users per year by 2005 (para 2.4.4): "Encourage all couples with unmet need to use terminal or spacing methods based on their choice, and to substantially reduce the current unmet need, increase the number of new users of sterilisation services to at least 10 lakh couples and provide spacing services to 30 lakh couples per year by the year 2005. This is a complete reversal of the Target Free Approach (TFA) announced by Government of India (GOI). It also violates Article 12 of CEDAW, later reaffirmed by the International Conference on Population and Development (ICPD), underscoring the "*right of all couples and individuals to decide freely and responsibly on the number, spacing and timing of their children... and the right to make decisions concerning reproduction free of discrimination, coercion, and violence*" (ICPD POA, Paragraph # 7.3).

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71 Women's Group Memorandum (Andhra Pradesh).

### III. Medicines causing teratogenic effects

Since many medicines taken during pregnancy can cause congenital malformation of the unborn baby, reproductive health concerns should address the use of medicines, x-rays and chemicals during pregnancy. The case of thalidomide prescribed to pregnant women for morning sickness was associated with over 40,000 children being born without hands and legs in Europe.

Di Ethyl Stilbaestrol (DES) was promoted for making normal babies more normal and given for threatened abortion. Review of the studies showed higher incidence of abortion in pregnant women who were prescribed this drug. Daughters born to women prescribed DES in pregnancy on reaching adulthood were found to have high incidence of an extremely rare cancer of the vagina; this called for surgery of their genital area resulting in their inability to have normal married lives.

High dose estrogen progesterone (HDEP) combination used for pregnancy testing, secondary amenorrhea and for menorrhagia endometriosis as well as threatened abortion was found associated with abnormalities of the skeletal system, neurological system, limb defects, problems with the heart, kidneys etc. All the above drugs were produced and marketed as safe products. Knowledge about the teratogenic effect was denied by the manufacturers and not provided to the doctors and the patients, even when known to the manufacturers.

The EP Campaign launched on International Women's Day and public litigation in the Supreme Court resulted in banning of the drug eight years later and changes in the drugs and Cosmetics Act (Shiva 1996). The right to unbiased information and safe product, and safe ethical clinical trials in matters related to medicines must be safeguarded at the national and international level. Ethical guidelines for bio-medical research in human clinical trials concerning contraceptive and reproductive technologies are currently being formulated. If these were diligently implemented, violations would be dealt with severe legal action.<sup>73</sup>

### IV. Medical Impact of the Bhopal Disaster

Various studies conducted by NGOs have pointed out that the medical consequences of the Union Carbide disaster have been under-assessed by the ICMR and certain exposure related injuries have been overlooked.

The pregnancy outcome survey referred to above was carried out by Medico Friend Circle in September 1985 and showed that the rate spontaneous abortions rate among women exposed to the gas was several times higher than that reported by ICMR. A survey of psychiatric morbidity carried

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72 Reference: *National Profile of Women, Health and Development*, Dr. Sarala Gopalan & Dr. Mira Shiva.

73 ICMR 1999.

out by a group of independent doctors from Bombay found that nearly 40 percent of those exposed suffered from post-traumatic stress disorder, a condition not studied by ICMR.

An epidemiological survey coupled with clinical investigation carried out by the International Medical Commission on Bhopal, comprising 14 medical specialists from 11 different countries, in January 1994 reported significant multi-organ symptoms persistent among the exposed population. Clinical examinations have shown significant lung impairment, marked reduction in control over limb movements and reduced memory function caused due to exposure. Their findings include evidence of a range of neurotoxic injuries in the exposed population.<sup>74</sup>

Most of the information on the medical consequences of the Union Carbide disaster in Bhopal has been generated by the Indian Council of Medical Research (ICMR), an agency of the Indian Government that carried out 25 research studies from 1985 to 1994. All ICMR studies on Bhopal were prematurely terminated by December 1994.

## V. Mental Health

The hysterectomy controversy in the early 1990s in Pune represents another aspect of the control and decision-making within custodial institutions. The hysterectomy of girls below 18 years of age, in Pune in 1993 who were mentally retarded, raised questions about the decision made by the health professionals. The professionals involved neither denied that the hysterectomy was being done, nor did they did see it as a violation. It was justified as being in the best interests of the hygiene of the mentally retarded girls, as making practicable the care of the mentally retarded. The response did not rule out the possibility of sexual abuse within the institutions, but said it would protect the girls from pregnancy in the event of such an encounter. The persons responsible for the decision responded angrily to the charges of human rights violations. The Medical Council of India, however, distanced itself from this position, and declared the practice as being against their norms. The intervention of the media and the human rights community precluded further hysterectomies from being done.<sup>75</sup>

The more recent incident in Erawadi asylum in Tamil Nadu, where mental patients tied to posts were burnt alive in a fire accident, points to the utter disregard of both society and the State as regards the rights of mental health patients. The fact that families customarily abandon the mentally ill is itself deplorable. Moreover, the fact that the State allows that practice to continue and permits the patients to languish in inappropriate conditions as in Erawadi or many such privately owned hovels, speaks volumes of the State's abdication of responsibility towards the mentally ill.

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74 *Surviving Bhopal 16 years on: A Fact Finding Mission*, The Other Media, New Delhi.

75 *Mapping of Human Rights*, Usha Ramanathan.

## VI. Sexual Assault - Medico-legal Abuses

The increased reporting of sexual assault, the incidence of rape and in particular gang rape of women across the country is especially alarming as is the use of systematic rape and sexual violence as a strategy for terrorising and brutalising women in conflict situations and communal violence. Rape by economically or socially powerful persons misusing their positions to sexually exploit women can be seen in the large number of cases of the rape of poor women, particularly in rural areas. Dalit women are the main targets of landlord gangs who use their vulnerability to sexually exploit them. Adivasi women are victims of forest guards and contractors. In a large number of cases the women do not even report the cases because they feel that it will be of little help given the strong economic and social clout of the aggressors.

Rape is one of the most brutal forms of aggression against women and shakes the foundation of the lives of the victims. In addition to the trauma of rape itself, the victims have to suffer further agony during the legal proceedings. The recent Gujarat carnage, which witnessed numerous cases, is enough to substantiate this point. Added to this is the reluctance among the medical community to identify such incidences as sexual assault. In Gujarat, there have been many reports of women coming to hospitals in conditions that should have prompted doctors to certainly suspect sexual assault. Yet doctors in hospitals visited by the fact-finding team stated that no cases of sexual assault had been filed. In other words, doctors seem to have disregarded obvious signs of sexual assault. Consequently, there was no medical evidence, on the basis of which women could seek justice.

Existing services do not acknowledge women's health needs. Also, the lack of privacy in services through camps prevents them from seeking treatment. There is no effort to make existing services more accessible to women. Hundreds of women have given birth in the camps, assisted largely by local volunteers, and without any facilities. These women, as well as those in curfew-bound areas, are not in a position to seek specialised health services.

Survivors of sexual violence have little access to counseling and issues relating to their sexual and reproductive health and rights are neglected. Very little attention has been paid to issues relating to pregnancy, abortions and sexually transmitted infections as a consequence of sexual violence, and there is an appalling lack of safe spaces for women to recover and defend themselves.<sup>76</sup> There is no acknowledgement of the need to provide treatment for post-traumatic stress disorder, a well-known consequence of any disaster. By ignoring the significance of psychological trauma, the services are under-estimating the scale of damage and undermining the need to rehabilitate the affected.<sup>77</sup>

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76 *Carnage in Gujarat, A Public Health Crisis*, MFC Report, 2002 and *Survivors Speak* - Citizens Initiative.

77 *Carnage in Gujarat, A Public Health Crisis, 2002*, Medico Friend Circle Report By International Initiative for Justice.

## VII. Sexual Minorities and the Mental Health Profession

The denial of rights has come out sharply in case of “reparative therapies” by mental health professionals to “treat” same-sex-desiring people. Reparative therapies aim to change the sexual orientation of a patient through the administration of nausea inducing drugs, shock therapy and/or behavioral therapy. The following quote describes one gay man’s experience with reparative therapy:

*“I approached a psychiatrist, assuming he would help me. ‘Help’ he did. “Its all in the mind”, he said. My bouts of depression (which I never realised arose from bottling up gay orientation) he glibly informed was a disease called schizophrenia. “Your gayness is the cause of delusions and hallucinations.” He prescribed ‘Orap’ and ‘Serenace’ which are powerful neuroleptic medications. The nightmare began in earnest, lasting fifteen years, ravaging body and soul. I took an overdose of Orap hoping to die. I did not. I was rescued. As a reward, I was given shock therapy, which played havoc with my memory for over two years. My moods were always bleak, my senses dull, and my thinking blurred.” -Hemant, quoted in Narrain and Khatia*

Arvind Narrain and Tarunabh Khatia, in a paper entitled “Medicalisation of homosexuality: a human rights approach,” discuss the glaring problems of reparative therapy, so vividly described by Hemant. The first is the fact that reparative therapy assumes homosexuality to be a pathological condition requiring medical modification, rather than an expression of sexual freedom, choice and diversity. Secondly, the use of nausea-inducing drugs and electric shock, for example, not only violate the dignity of a patient, but also, at worst, constitute forms of torture. Thirdly, the philosophy of reparative therapy, premised as it is on the notion that homosexuality is an illness, assumes that all these same-sex desiring clients are ultimately in need of “conversion.” The details, desires and concerns in a client’s life - as well as a therapist’s own biases - are rendered irrelevant (Narrain and Khatia).

The following case study from Delhi, also provided by Narrain and Khatia, localises this discussion of the interface between same-sex sexuality and the right to health.

*“A petition was filed in the case of a patient from the All India Institute for Medical Sciences (AIIMS) who was being treated by a doctor at AIIMS psychiatry department for the past four years so as to cure him of his homosexuality. The patient himself noted that, “Men, who are confused about their sexuality, need to be given the opportunity to go back to heterosexuality. I have never been confused but was nevertheless told that I had to be ‘cured’ of my homosexuality. The doctor put me on drugs which I have been taking for four years.” The patient went to Naz Foundation India (an organisation working on MSM issues), and the coordinator of the MSM Project, Shaleen Rakesh filed a complaint with the National Human Rights Commission (NHRC) alleging psychiatric abuse involving a patient at AIIMS. The treatment reportedly involved two components: counseling therapy and drugs. During counseling therapy sessions, the doctor explicitly told the patient that he needed to curb his*

*homosexual fantasies, as well as start making women rather than men the objects of his desire. The doctor also administered drugs intended to change the sexual orientation of the patient, providing loose drugs from his stock rather than disclosing the identity of the drug through formal prescription. The patient reports experiencing serious emotional and psychological trauma and damage, as well as a feeling of personal violation. The moment the petition was filed there was a wide mobilisation of the sexuality minority community and a number of letters were written to the NHRC urging the NHRC to protect the rights of the sexuality minority community. The NHRC after admitting the complaint (No. 3920) finally choose to reject it. Informal conversations with the Chairman of the NHRC revealed that the Chairman believed that till Section 377, Indian Penal Code<sup>78</sup> went nothing could be done and anyway most of these organisations were foreign funded and there was no real grassroots support. According to another NHRC source, "homosexuality is an offence under IPC, isn't it? So, do you want us to take cognizance of something that is an offence?" (The Pioneer, Thursday, August 2, 2001).*

Among the many things to glean from this case study is an awareness of the ways in which mental health, law and culture collude in the violation of the rights of sexually marginalised people and the active obstruction of their realisation of the right to health.

## **VIII. HIV / AIDS - Socioeconomic and legal discrimination**

In Kerala last year, two young children living with HIV/AIDS were forced to change their school repeatedly because of their HIV status. Parents opposed the inclusion of the two HIV-positive children in schools in which their children were studying. Sensitisation efforts of school authorities were half hearted and they completely failed to take a strong stand on the inclusion of the two children in their schools. The children's grandfather was forced to go on a hunger strike before the government paid attention to their plight. Finally, in March this year, after a sustained media campaign, the government decided that the children would be tutored at home. Such a decision only reinforced the children's sense of isolation and failed to protect their right to equality. Nevertheless, this case is not unique to Kerala.

In Hyderabad, three HIV-positive siblings were denied admission by schools since the managements of the school was against accepting HIV-positive children. These schools disregarded the order of the Andhra Pradesh government, that educational institutions should not discriminate against anyone and must admit HIV-positive children. The youngest of the three siblings has already succumbed to HIV and the surviving two siblings are presently being tutored by an NGO. A case with respect to the right to education of these children is pending in the Andhra Pradesh High Court (ibid).

In Nippani (Karnataka) the work of SANGRAM VAMP, an NGO that has successfully promoted condom use among sex workers and their clients, came to a standstill due to police abuse in early

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78 S.377, IPC has been used to criminalise even consensual sexual relationships between people of the same sex. It reads thus: "Whoever voluntarily has carnal intercourse against the order of nature with any man, woman or animal shall be punished with imprisonment for life..."

2002. Persistent harassment of the women in the group eventually resulted in the disbanding of the organisation. It also led to the eviction of most of the peer educators from their homes, hence interrupting their work that had resulted previously in the distribution of 350,000 condoms per month. When the peer educators tried to file a police report against the persons who had attacked them, the local police chief refused to take any action and was of the view that women in prostitution were not “normal citizens.” In Bangalore, police committed severe abuses against peer educators who worked with an organisation called Samraksha. Police refused to recognise the identity cards issued to the peer educators, severely beat the women while in detention, and tried to link them to false narcotic charges and also accused them of promoting prostitution (ibid).

In *Lucy D’Souza v. State of Goa*, the court held that if a person tests positive for HIV, the government may isolate such a person in the interests of healthcare; the individual’s right to liberty must be balanced against the public interest. However, it has also been held that every doctor, whether at a government hospital or otherwise, has the professional obligation to extend his services with due expertise for protecting life without discrimination. This is a fundamental principle for healthcare included in the Indian Medical Council Regulations 2002, which states “no physician shall arbitrarily refuse treatment to a patient, except for good reason”, and in the case of an epidemic, “the physician should not abandon his duty for fear of contracting the disease himself.”

## **Violation of a single constitutional right simultaneously jeopardises other rights**

Driven largely by the agenda of developed Western countries and international financial institutions, the Indian State’s concern for its ever rising population, and its consistent failure to check birth rates, has given birth to a population policy that violates the Directive Principles of the Indian Constitution, as well as several International Covenants that India is signatory to, including the Beijing Platform of Action and the Cairo Declaration.

The birth of a third child beyond a period of gestation from the commencement of state laws on the subject (including Madhya Pradesh, Rajasthan and Haryana) will disqualify a person from standing for elections to the panchayat, or to continue in office.

The third child in certain regions of the country under this norm is denied access to PDS facility, free education and other welfare schemes whereas the mother is denied maternal benefits. These have serious consequences for the health of both the mother and children and are a clear violation of the Right to Health and Right to Food dictum.

Instead of working towards resolving root causes of social problems, the State is choosing retrogressive measures like the enactment of such undemocratic laws. On the other, it has also actively withdrawn

from its responsibilities towards its people. Furthermore it violates the Articles of CESCR. Thus to achieve Right to Health for all, realisation of other human rights is not only necessary but also essential.

**Article 12: The right to the highest attainable standard of health**

The right to health is closely related to and dependent upon the realisation of other human rights, as contained in the International Bill of Rights, including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement. These and other rights and freedoms address integral components of the right to health.

In compliance with the fundamental obligations laid down in article 12 of this Convention, States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour or national or ethnic origin, to equality before the law, notably in the enjoyment of these rights.

In conceptual understanding as we say that health is a socio-economic concept and thus for a “positive” right as compared to the “negative” right we need to stress on the actual interventions that are required for a positive right to operate. Thus, highlighting violations is just a beginning, but not an end, as one needs to develop strategies as to how quality healthcare or the determinants of health could be made available, accessible, and acceptable. This is important because while strategies to make health a political issue are necessary, they are not sufficient to ensure that there would be universal non-discriminatory access to quality services, nor can they on their own usher in a system based on human rights principles. This document will thus look at the strategies to establish the right to health and cite interventions that have worked, as such a framework would have the potential to channelise the human rights framework into activism at the ground level.

## Chapter 5

# Strategies to Establish the Right to Health

India has a long history of social interventions and reforms involving a wide range of issues, not all of which may have had the rights approach. However, many of these have resulted in encouraging outcomes. There is also a long history of social organisations and movements using the legislature innovatively to secure social justice. The Indian legal system, despite its colonial legacy, is known and respected for issuing landmark judgments that have changed the course of history, laws and the way issues are perceived and dealt with. While acknowledging this positive aspect of our history, it must also be admitted that the success rate of securing social justice - through mass interventions and courts - has been low, especially for the poor and marginalised sections of the society. For this section, violation of rights is a daily feature of their lives, many of which are not even perceived as violations.

When it comes to health, common perception regards doctors as Gods and the failure of medical treatment (resulting in inevitable death) as destiny. Healthcare is seen as a service that the State provides as an act of generosity. But the quality of healthcare or the facilities that provide healthcare is often dependant on other factors, like availability and affordability. It is only the rich who can 'buy' medical treatment and services. However, most people cannot connect patterns of ill health — and other indices of social exclusion that are closely associated with poverty - with patterns of social spending and systematic policy decisions on the part of the government. So there is a tendency to overlook the responsibility of the State to respect, protect, promote and fulfill — or to hold the State responsible — for violating the right to health or any of the associated rights. Unfortunately, the NGOs, social action groups and mass organisations too often fail to see these linkages.

Therefore, the foremost task seems to be the initiation of a process through which the perception of health as a human right can be transmitted to citizens/communities at large. Simultaneously, however, it is also a task to educate the 'providers' that their duty is to respect the rights of their patients, and it is not a favour they are granting. This perception then needs to impact upon the decision makers in the government, international financial institutions, and multinational corporations, who also must begin to see health and healthcare as non-negotiable entitlements, and not as matters of governmental largesse or profitable business.

The achievement of this central goal will not be easy, because it involves change of attitudes, power relations, vested interests and much more. It is evident that a multi-pronged strategy is necessary to initiate any intervention to this end. Yet there has to be a beginning somewhere. Some of the concrete strategies to achieve this central goal could be as follows:

## 1 Mobilisation at the grassroots

- Mobilise communities and groups from a right to health perspective and initiating local interventions to raise consciousness about human rights.
- Analyse local situations from a rights perspective, identify violations taking place at the local level (specifically around right to health, as well as other rights) and take necessary action wherever possible.

### Implications of the two child norm on Panchayati Raj Institutions

Sama - Resource Group for Women and Health and MP BGVS conducted a study in eleven districts of Madhya Pradesh to document and analyse the implications of such a norm on representatives in PRIs; particularly to highlight the implications of the state government's decision to enact this norm through the State Population Policy as well as the Panchayati Raj Act.

The Madhya Pradesh Population Policy 2000 states that persons having more than two children after January 26, 2001 would not be eligible to contest elections for Panchayats, local bodies, mandis, or cooperatives in the state. In case, they get elected and in the meantime they have the third child, they would be disqualified for the post.

Apart from this population policy, the Panchayati Raj Act, under section 36, D (1) states that after January 26, 2001 a person having a third child will be removed from the post as a panchayat member, will not be eligible to contest the elections and no development projects will be given to such a person.

The study highlighted the following implications:

- Disproportionately affects marginalised groups / communities: The norm deterred large sections of dalits, adivasis and poor from contesting elections in the PRIs, depriving them of their democratic rights. About 82 percent of all disqualified persons belonged to Scheduled Castes (SCs), Scheduled Tribes (STs) and Other Backward Classes (OBCs). Women constituted almost 39 percent of those disqualified from the SCs and STs.
- Increases violence against women: The study found that the women bore a double burden as representatives in PRIs as well as spouses of representatives. There was a definite increase in abortion, desertion (sending wife to her natal home to hide the third pregnancy or child), accusing women of extra marital relations(to disclaim the third child) and sterilisation.
- Encourages sex selective abortions and female infanticide in the context of son preference, worsening the already alarming sex ratio in the country.
- Giving up the second or third child ( usually the girl child) for adoption.
- Disastrous consequences on already marginalised populations- particularly women, dalits and the poor, due to withdrawal of welfare measures by the state.

- Reorient and initiate rights based perspective among field level health providers.
- Disseminate information relating to the right to health, in order to support ground level mobilisation and interventions.
- Initiate immediate fact-finding studies / investigations in places of crisis from a rights perspective. For example, MFC (Medico Friend Circle: 2002) started a Fact Finding Study during the Gujarat carnage and investigated the health impact of the unrelenting and horrific violence in Gujarat and the role played by the public health system. International Initiative for

Justice in Gujarat (2003) looked into the issue of sexual violence in conflict situations and emphasised the critical intervention on the part of the State and civil society.

## **2 Involvement in advocacy, organisation and affiliation with campaigns at various levels around the right to health**

- Organise, assist and participate in local campaigns.
- Initiate state-wide and nation-wide campaigns.

### **Jan Swasthya Abhiyan (People's Health Movement, India)**

This is an exemplary campaign, which was initiated in Savar near Dhaka, Bangladesh, where representatives from 93 countries came together for the Peoples Health Assembly (PHA) on 4th December 2000. The objective of this assembly held at the end of the year 2000 was to give a call to renew the pledge of 'Health for All.' Though the goal committed by Governments at Alma Ata was "Health for all by the year 2000", this goal had been subsequently marginalised in health policy discussions, and as the year 2000 approached, was quietly being forgotten by Governments around the world. The assembly also aimed to build global solidarity, and to bring together people's movements and organisations working to advance people's health in the context of policies of globalisation.

A total of 1350 delegates participated in PHA, of which about 180 were from India, sponsored by the National Coordination Committee of the Indian campaign. Prior to this, the India National Health Assembly at Kolkata was organised on November 30th and December 1, 2000, where as the culmination of a very extensive mobilisation across 19 states, a massive number of over 2000 delegates congregated. This National assembly declared the major goals of the Indian People's Health Movement, and demarcated the specific issues on which the people's health movement in India would concentrate. The national networks and organisations that had come together to organise the National Health Assembly, decided to continue and develop this movement in the form of the Jan Swasthya Abhiyan (JSA), which forms the Indian regional circle of the global People's Health Movement.

The JSA at the national level is the coalition of the networks of voluntary organisations and peoples' movements involved in healthcare delivery and health policy, who made themselves a part of the Peoples' Health Assembly campaign in India in the year 2000, and have continued to participate in this process. These national networks have numerous constituent organisations, which implies that a few hundred organisations are involved directly in the national process. Outside of these networks, several hundred other organisations have been involved at state, district and block level activities across the country.

Source: JSA Brochure, 2004

- Establish active intersectoral and interdisciplinary linkages.

It must be acknowledged that there is a lack of intersectoral communication between social action groups and NGOs. Rarely does a group working with health feel the sense of 'ownership' of issues such as labour, housing or dams, if there is no direct component of the traditional notion of health in such a collaboration (and vice versa). At another level, a group or a body working with health may require specialised expertise of groups involved with subjects like demography, epidemiology or toxicology, in order to have technically sound evidence of violations. Such collaborations are important in a human rights framework.

- Organise, assist and participate in public tribunals, Jan Sunvais, etc.

- Build a mechanism by which local groups can access services of human rights lawyers and legal aid organisations/groups in order to address specific cases of violation.

### Documentation of cases of denial of healthcare

On the 5th and 6th of September 2003, a National Workshop and National Public Consultation on the Right to Healthcare was organised by Jan Swasthya Abhiyan. The public consultation, which was in the nature of a public hearing, was conducted in the presence of Justice Anand, Chairperson of the National Human Rights Commission. It was attended by over 250 delegates from 16 states dedicated to a broad spectrum of health and rights-based movements including rights for women, children, people affected by HIV, displaced people, people in areas of conflict, workers in the unorganised sector, as well as a number of academicians, policy analysts and other interested citizens.

As a part of this emerging campaign, documentation of cases where the denial of healthcare has led to death, permanent disability or financial loss was initiated by organisations from various states, from June 2003 onwards. The cases were documented according to the protocols prepared in English, Hindi and Marathi. JSA also designed a leaflet giving guidelines to the activists about how to document the cases and prepared a framework for analysis of these cases.

During this process representatives of JSA also interacted with members of the NHRC, particularly the Chairperson, Justice Anand and Convener of the Health Committee, Dr. Srinath Reddy, to update them about the developments and to explore channels of involving the NHRC in facilitating the campaign. Based on this interaction, Justice Anand was invited to inaugurate the National Public Consultation on 6th September. It was felt that the active involvement of the National Human Rights Commission would add to the strength and legitimacy of the process.

The afternoon session on the 5th of September was an interactive session where participants divided into language wise groups and shared experiences of the denial of healthcare. There were about 70 cases, from which the following were selected to be presented on the 6th of September. The names of the people have been changed, but they represent the spectrum of challenges faced by people in accessing basic healthcare.

- Sucheta Devi was motivated by the Auxiliary Nurse Midwife to undergo sterilisation at the tubectomy camp in Halharmau Primary Health Centre, in Uttar Pradesh. She was made to sign papers, but not explained their contents, and nature of information. Although the procedure is a minor and routine one, she passed away during the operation. The relatives of the deceased were not informed of her death and all the staffs, including the doctor left the center. Members of her family found her dead body on a stretcher outside the operation theatre.
- Anita, a 12-year-old girl, from Malakapur was bitten by a rabid dog. She was taken to the district hospital in Moradabad, but not given the anti-rabies vaccine. She died after a period of time. Three others from the same village, who had also been bitten and were denied the vaccine, succumbed to rabies.
- Namdeo, a resident of Thane district was bitten by a snake. He was first taken to the Primary Health Center in Saralgaon, Maharashtra, where, due to non-availability of anti snake venom, he was referred to the Murbad Rural Hospital. The rural hospital did not have the anti snake venom in stock either, and his relatives were advised to purchase the medications from a private pharmacy. After procuring the medicines, he was asked to wait in line, instead of being seen on an emergency basis. Namdeo died the same day.
- One year old Asha, a resident of Mokhada, Thane district, Maharashtra had fever and difficulty in breathing (pneumonia). Two visits to the Primary Health Center (PHC) proved futile, as there was no doctor. They finally went to a different PHC, where the doctor told them there was no bed for the child. She was placed in a neighboring home, where she was being treated. After the doctor left, there were no trained personnel and the baby died that night.

- Chintu and his family of three, father, mother and sister were all suffering from Tuberculosis. Dr. Sen of West Bengal referred them to the government hospital for treatment of TB, through the DOTS program. They were refused DOTS treatment because they did not have a ration card, and their name was not on the voter's list. When Dr. Sen next met Chintu, his father and little sister had succumbed to tuberculosis and died.

In response to the presentation of cases of denial of care, Justice Anand said that the cases were "heart-rending." He was aware of the numerous cases of neglect of patients and callous treatment, as he had heard of them as a judge and Chief Justice of the Supreme Court. He recounted a case in which a patient with a head injury was transferred through 7 public hospitals in the span of 12 hours, only to be treated in a private hospital. He shared JSA's stand that the National Human Rights Commission (NHRC) should hold regional consultations on the right to healthcare. JSA will continue to document cases of clear denial to healthcare to be officially recorded by the NHRC. This will provide the foundation for initiating a process of official inquiry process as well as widespread public debate to goad the official machinery into making amends.

Source-Report of the National Workshop on Right to Healthcare and National Consultation on Healthcare as Human Right, Organised by JSA. Report by CEHAT, Mumbai, 2004.

- Create awareness about patients' rights.

### **Proposed Charter of Patients' Rights**

Prepared by Working and Support Groups for Quality Assurance in the Brihanmumbai Municipal Corporation (BMC) with Women Centred Health Project (WCHP)

#### **Right to access**

1. Right to basic healthcare, expensive life saving treatment and emergency services at hospitals irrespective of ability to pay.
2. Right to easy access to adequate and appropriate health services that are effective and sensitive to community's needs.
3. Right to expect prompt treatment within available resources in an emergency irrespective of the ability to pay, in the work hours of the primary and secondary healthcare facilities and at all times in the casualty departments of the secondary and tertiary hospitals.
4. Right to have access to appropriate redressal procedures.
5. Right to easy access to adequate and appropriate health services that are effective and sensitive to community's needs.

#### **Right to referral**

6. Right to be referred to hospital/ consultant wherever applicable as per the referral protocols.
7. Right to be transferred to another healthcare establishment only after an explanation of the need for transfer and after the other establishment has accepted the patient.

#### **Right to respect**

8. Right to polite behaviour and considerate care.
9. Right to refuse to participate in human experimentation, research project affecting his/her care or treatment.

#### **Right to information**

10. Right to information on causes, diagnosis, treatment, medicines and preventive measures for a particular condition.
11. Right to information about expected outcomes, side effects, after effects, chances of success, cost and availability of prescribed medication.

### **Right to confidentiality**

12. Right to expect that all communication and records pertaining to his/her care be treated as confidential.

### **Right to informed consent**

13. Right to clear, concise explanation in lay terms of proposed procedures and available alternatives. Wherever applicable the explanation should include information on risks, side effects, problems relating to recuperation, likelihood of success, and risk of death. Informed consent must be obtained prior to the conduct of treatment or a procedure. In case of a minor, consent must be obtained from the parent or guardian. If a patient is incapacitated or any delay would be dangerous, the doctor is entitled to carry out the procedure after a second opinion is obtained.

(Complied from Pondicherry Declaration on Health Rights and Responsibilities)

Advocacy For RTI Services Within BMC; National consultation on Advocacy and Monitoring of Women's Health and Rights: Many Voices- One Agenda; 26th to 28th June 2002.

## **3 Intervention at the policy level**

- The principle that State is responsible for policy, control, and delivery of free, basic health services, easily accessible to all should be at the root of national and international health policy.
- Assimilate Directive Principles with Fundamental Rights through a constitutional amendment<sup>79</sup>.
- Incorporate a National Health Act (similar to Canada Health Act)<sup>80</sup>, which will organise the present healthcare system under the common umbrella.
- Increase allocation of health budget even at the cost of military and ammunitions and not the other way round.
- Adopt locational policies for setting up of Primary Health Centers (PHCs) and Hospitals i.e. maintaining the prescribed ratio.
- Develop People's Health Charter (See Annexure 2) and declare health as a justiciable right and demand the provision of basic healthcare as a fundamental constitutional right of every one
- The focus of Health policy and action towards the underlying, social, economic, and political causes of avoidable disease and death.
- Work with national human rights bodies, such as NHRC, National Commission for Women (NCW) or the minority and tribal commissions, etc.

## **Public Hearing on Right to Healthcare : NHRC and JSA**

A National Public Hearing held in Delhi with recommendations and an action plan for the government, civil societies to ensure quality of healthcare. The National Hearing on Right to Healthcare was organised by JSA and NHRC on the 16th and 17th of December 2004.

Recommendations for a National Action Plan to operationalise the right to Healthcare within the broader framework of the Right to Health, evolved from this hearing. (Details in Annexure 3)

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79 Operationalising Right to Healthcare in India.

80 Canadian Healthcare - The University Model Evolving, Greg Connolly, Global Health Council, 2002.

- Engage in dialogue with Parliamentary Committees and similar bodies to promote the concept of right to health.

### **Save public health - make healthcare a fundamental right!**

#### **Jan Swasthya Abhiyan dialogue with political parties before general elections**

Jan Swasthya Abhiyan organised a public dialogue on Health issues on 12th March 2004 at the Constitution Club, New Delhi. Around 300 people attended the public dialogue on Health issues, including representatives from the JSA state units (Delhi, U.P., Haryana, Rajasthan, M.P., Chattisgarh, Maharashtra and Karnataka), representatives of different political parties and the media. Taking the forthcoming elections as an opportunity, the dialogue aimed at making the political process in the country cognizant of the present state of healthcare and seeking their commitment in making healthcare a fundamental right. Besides this, the other important aspect of the dialogue was demanding an increase in the budgetary allocation for public health.

- Legal Intervention.
- Learn from international experiences.

There is a need for the human rights groups of this country to keep in touch with past experiences and developments in other countries, especially those of Latin American countries, as these countries have already undergone similar processes of structural adjustment programmes and programmes dictated by international finance organisations, against which human rights groups have evolved interesting ways of interventions, legally and socially.

- Engage in dialogue with the legal establishment.

Most of the time, the national legal machinery is not even aware of provisions and obligations provided in various human rights instruments and their interconnections. Even if there is familiarity with the ICCPR, it may not be the same for treaties such as ICESCR, CEDAW, CRC, etc.

- Inform and popularise legal and constitutional provisions that entitle people to demand, implement and monitor the healthcare system. For example,
  - ❖ 73rd Amendment of the Constitution, which empowers Gram Panchayat to plan and implement provisions in the social sector.
  - ❖ Under the Control Act, the Gram Sabha is competent to control institutions of the social sector.
- Involve in a larger level of human rights advocacy, in an attempt to:
  - ❖ Redefine and clarify the normative content of rights and obligations prescribed by different human rights instruments and treaties.
  - ❖ Effect changes in legislations, incorporating new ideas, issues, understandings, interpretations and perspectives.

- ❖ Lobby for the adoption and ratification of international treaties and conference declarations that enshrine the right to health.
- Establish a body of human rights and social action groups across issues and sectors to monitor and review violations and realisation of the right to health, as well as the other interconnected rights.
- Participate in the process of monitoring and review at the international arena by engaging with the committees responsible for monitoring treaties, such as ICCPR, ICESCR, CEDAW, CRC and others that recognise the right to health. For example, the International Initiative for Justice in Gujarat (IIJ) brought together a panel of feminists, jurists, activists, lawyers, writers and academicians from all over the world. The IIJ team came together as an expression of solidarity with feminists from India to draw international attention to the very concrete impact of violence on the lives of ordinary Muslim citizens of Gujarat. This investigation has been used to shatter the silence of international governments and other international agencies like the UN bodies and Special Rapporteurs.<sup>81</sup>

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81 *Threatened Existence: A Feminist Analysis of The Genocide in Gujarat, International Initiative For Justice*, December 2003.

## Press Release: Why Women's groups oppose Injectables

On October 29, 2004, women's groups in Delhi released a statement to the press opposing hormonal injectable contraceptives, which are hazardous to women's health. This was in response to the workshop held in Manesar on 27-28 October 2004, organised by some non government organisations in collaboration with the government to "expand choices of contraception."



The strategies however are interrelated and interconnected and to achieve a single goal a number of strategies in different combinations can be used depending on the kinds of violations and needs that have to be addressed.

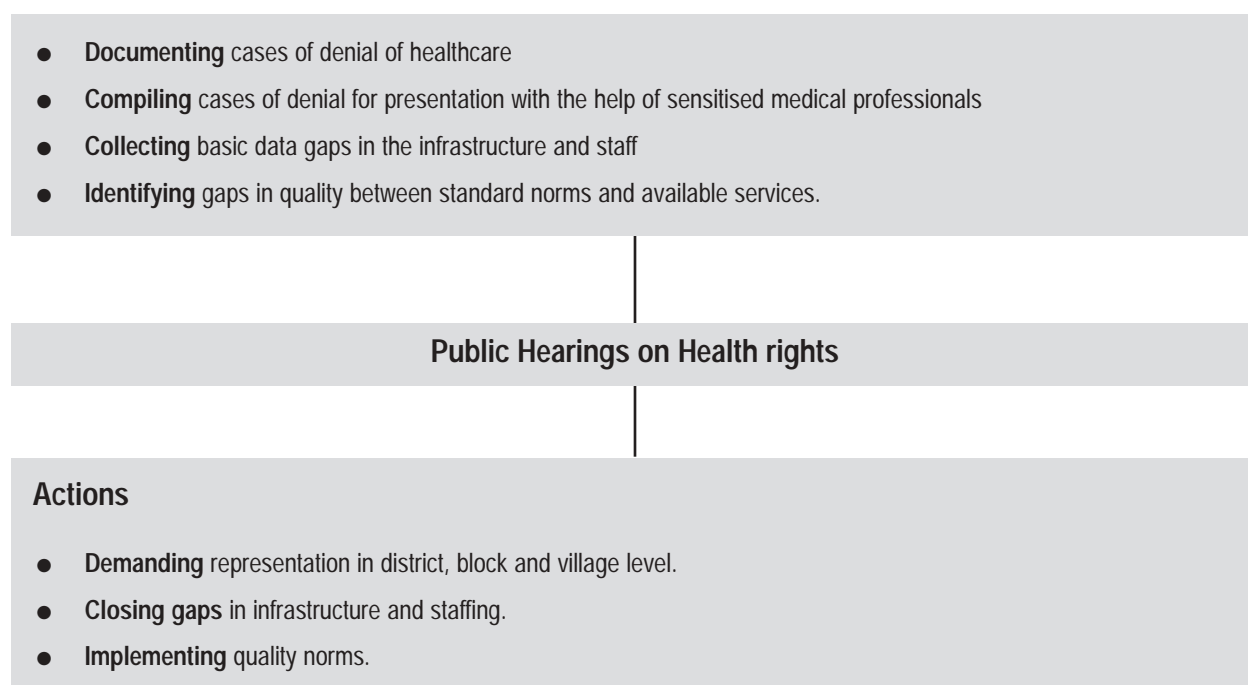
## What we need to do to make the Right to Healthcare a reality

To have a comprehensive idea of the strategies discussed, a Provisional Framework for the attainment of Right to Health and Healthcare developed by Jan Swasthya Abhiyan<sup>82</sup> is cited here.

### District Level

This process should involve all community health workers, elected bodies and local people's movements.

The district public hearings then feed into public interest litigations and regional NHRC public



hearings and vice versa. They also use the context created by such action at the national and state level to strengthen intervention at the district level.

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82 Report of the National Workshop on Right to Healthcare and National Consultation on Healthcare as Human Right, organised by Jan Swasthya Abhiyan, 2004.

## State Level

- Continuing documentation of cases of denial of healthcare.
- Conducting a situational analysis on Health Policy, including budget analysis and the status of state healthcare services. Guidelines for the analysis could be framed at the national level.
- Knowing the physical norms and the quality norms and monitoring them.
- Observing Peoples health week with presentation of State level status papers in all state capitals. This includes presentation of cases and situational analyses.
- Participating in National Human Rights Commission (NHRC) and State Human Rights Commission (SHRC) hearings.
- Raising basic issues of good administration/workforce in the public health services (build common ground with unions on this).
- Ensuring that adequate policy structure is in place for regulation of the private sector, for drug policy, for norms on service provision including referral services, for emergency health services, and for health worker programmes.
- Seeking judicial intervention where the government's own policy structure is violated or where policy is inadequate.

## National Level

- Preparing general guidelines for situational analysis on health policy as relating to Right to Healthcare in each state.
- Continuing documentation of denial of healthcare and submission to NHRC.
- Arranging for Regional Hearings on Denial of Right to Healthcare.
- Possible filing of Public Interest Litigations in key areas, such as right to basic health services, women's right to healthcare, right to essential drugs etc: March 2004.
- Interacting with parliament and legislature; national convention involving political parties to raise the issue of Right to Healthcare during General Elections: mid- 2004.
- Moving towards making the Right to Healthcare a Fundamental Right in the Constitution.
- Working towards patient friendly redressal mechanisms.
- Developing guidelines on range of costs for standard services.
- Involving diverse social sectors in a dialogue on the Right to Healthcare.

## Chapter 6

# Efforts that worked - A few Case Studies

### 1. Advocacy for Right to Healthcare - Experience of Kashtakari Sanghatana, an organisation working with tribals

In December 1997, a large demonstration was organised at the rural hospital, serving people in the area. The following were the main issues:

- Poor availability of drugs.
- Taking of bribes by staff.
- Inadequate attention to patients.
- Lack of people's participation in management of the Hospital/PHC.

This memorandum was read out before the people and staff of the PHC, and the staff was made to answer each question, one by one. The doctors were made to promise that they would treat patients as far as possible without arbitrary referrals to clinics and chemists. Several people related how a particular attendant had forced them to pay for certain services. This person was called before the people and he publicly apologised, promising not to do so in the future. A junior doctor also confessed to taking money from people for giving injections. A commitment was obtained from the staff that patients referred by the Health Workers would be given proper attention by them.<sup>83</sup>

### 2. Counseling of women victims of violence in a public hospital: the DILAASA project

Past and current research underlines the importance of the healthcare system in identifying women experiencing abuse, in helping them access other resources and in documenting and monitoring the extent and nature of violence in the communities they serve.

In India, there are burgeoning efforts in this direction. Given below is an example of an intervention in Mumbai that is trying to develop a health-based response to domestic violence.

With an aim to sensitise the public health system to gender and violence issues, CEHAT and the Public Health Department of the Brihanmumbai Municipal Corporation (BMC) have established Dilaasa at K B Bhabha Hospital, Bandra (West). *Dilaasa* means 'Reassurance' and it seeks to provide social and psychological support to women survivors of domestic violence. Dilaasa believes that every woman has a right to a safe home, right to a life without violence. There is no excuse for domestic violence.

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83 Abhay Shukla 1999.

## Services

1. Counseling: Trained counselors help women to build their strength so that they can rebuild their lives.
2. Legal aid: Through collaboration with Majlis and Lawyers Collective, legal aid is provided to women. Lawyers are available twice a week at the centre.
3. Temporary shelter: There is provision for temporary shelter for a short period at two shelters in the city. The hospital also provides 24-hour shelter under medical observation.

Training is one of the ongoing activities of the centre. The hospital staff is being sensitised to gender issues so that they are able to screen women survivors of domestic violence and refer them to the centre. A group of hospital staff has been trained as key trainers. A core group of 12 trainers comprising hospital staffs has evolved. They are now conducting trainings for the rest of the hospital staffs. The core group also has intensive discussions/debates and mock sessions to review their roles as providers and develop further as trainers.

### 3. Campaign against discriminatory population policies

In May 2002, following reports in some sections of the Press about a new “strategy paper” proposing return to the stringent population control measures, health groups and women’s groups took up the issue and submitted a petition to the NHRC. The petition also drew attention to several state government's population policies. The campaign group felt that these measures violate human rights and should not be included in the population policy. Signatures were collected for the petition from various organisations across the country to build a strong pressure group, not only in Delhi, but also in fairly remote corners of the country. The petition requested the NHRC to direct the states to comply with the directives and not to use population policies that deny basic rights.

After receiving the petition, the NHRC issued notices to the chief secretaries of the state governments mentioned in the petition and also convened a two day consultation . The states were asked to explain the questionable provisions in their population control policies. The campaign also translated the entire debate, disseminated it to the NGOs to raise awareness about the issue, so that they could engage in advocacy at the local level with their communities, who are at the final receiving end of such policies.<sup>84</sup>

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84 *Beyond Numbers: Politics of Population Policies*, Sama 2003.

NATIONAL HUMAN RIGHTS COMMISSION<sup>85</sup>  
(LAW DIVISION)  
SARDAR PATEL BHAVAN  
SANSAD MARG, NEW DELHI - 110 001

Tel.No.: 011-336 1611, 336 1671  
Fax.No.: 011-336 6537, 334 0016  
Telegraphic Add.: "HUMANRIGHTS"  
Home page : <http://nhrc.nic.in/>

Case No. 537/30/2002-2003-WC/UC

**NOTICE**

To  
THE CHIEF SECRETARY  
GOVT. OF MADHYA PRADESH, BHOPAL.

WHEREAS the complaint/intimation dated 24/05/2002 received from CENTRE FOR WOMEN'S DEVELOPMENT STUDIES in respect of POPULATION POLICY was placed before the Commission on 09/07/2002.

AND WHEREAS upon perusing the complaint the Commission has passed the following order.

*Issue notice to the Chief Secretaries of Andhra Pradesh, Rajasthan, Uttar Pradesh, Madhya Pradesh and Maharashtra for reply within six weeks.*

NOW THEREFORE TAKE NOTICE that you are required to submit the requisite information / Report within 6 weeks from the date of receipt of this notice.

TAKE FURTHER NOTICE that in default the Commission may proceed to take such action as it deems proper.

Given under my hand and seal of the Commission, this the day of 15 July 2002.



(BY ORDER)  
*[Signature]*  
ASSISTANT REGISTRAR (LAW)

Encl: Copy of the complaint.

- Note ->
1. The information / report shall be furnished only by the authority which is called upon to do so.
  2. Please quote the Case No. referred above in all future correspondence / reports.

#### 4. Occupational Health: SEWA Experience

SEWA, Ahmedabad has attempted to find solutions for problems created by occupational hazards. Women workers in the informal sector have the most physically exacting work, which they perform

with primitive tools. Women cart-pullers often transport 1000 kilograms over 6-7 miles a day, which may lead to miscarriages and fatigue. A re-designed handcart with rubber soled wheels meant less physical effort. What can be done about the persistent cough and consumption developed by beedi workers in tobacco grinding mills? A simple stool for the agate polishers of Cambay would lessen the strain on their backs and necks. SEWA has collaborated with the National Institute of Occupational Health, which has opened a Women's Cell with a sociologist, psychiatrist, gynaecologist (Sewa Report, 1984).

Such experiments need time, technical expertise and financial resources, which may not be available to many organisations. In another area, SEWA, Ahmedabad has shown that one way of bringing healthcare to people is by implementing existing health schemes. When doing a routine check on loan defaulters, SEWA found that many of its members, 35 out of 500, were unable to pay back their loans because of postnatal complications or death. After a dialogue with the government, SEWA became the intermediate body, which registered pregnant women, collected a minimal fee and gave health and financial assistance. When the government tried to push its family planning policy of two children per couple along with maternity relief, SEWA opposed it and demanded that maternity relief and services be provided to all women. Soon SEWA became involved in the training of traditional birth attendants or dais and Auxiliary Nurse Midwives. The Maternity Protection Scheme had proved to be an effective entry point into poor women's lives which encourages them to look after their health, decide the number children, as well as prepare the ground for unionising and development of programmes.<sup>86</sup>

## **5. HIV / AIDS - Supreme Court Verdict**

In the landmark case of *MX v. ZY* 1997, the Bombay High Court held that it is arbitrary, unjust and unlawful to dismiss a worker who is still qualified and fit to perform the requirements of the job, and who does not pose a risk to others on the job. (The petitioner who was a loader in a public sector company, was removed from the roster of casual labourers and his casual labour contract was cancelled, when he tested HIV-positive). The courts have also acknowledged that mandatory pre-employment testing is not acceptable. Any rule mandating medical fitness, as a prerequisite to employment must have the objective of assessing the person's capacity to fulfill the job's requirements and the extent to which s/he poses a threat or health hazard. Therefore, it is unlawful to terminate employment on the basis of HIV status unless s/he is not medically fit to do the job or there is a significant risk to the safety of other workers. India is also one of the few places where compassionate employment is granted to survivors of deceased HIV-positive employees of the State, upholding the right to earn a livelihood under Article 21 of the Constitution.

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86 *Recognising Right to Health, Issues at Stake, Theory and Practice in the Contemporary Women's Movement in India*, Nandita Gandhi and Nandita Shah, Kali for Women.

## Annexure I

# International and National Instruments that discuss Right to Health

## I. Universal Declaration of Human Rights (UDHR)

*Adopted and proclaimed by General Assembly resolution 217 A (III) of 10 December 1948*

### **Article 25**

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

## II. International Covenant on Economic, Social and Cultural Rights (ICESCR)

*Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966.*

Entry into Force: 3 January 1976, in accordance with Article 27.

### **Article 12**

1. The States Parties recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realisation of this right shall include those necessary for:
  - a. The provision for the reduction of the still birth rate and of infant mortality and for the healthy development of the child.
  - b. The improvement of all aspects of environmental and industrial hygiene.
  - c. The prevention, treatment and control of epidemic, endemic, occupational and other diseases.
  - d. The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

### **III. International Covenant on Civil and Political Rights (ICCPR)**

*Adopted and opened for signature, ratification and accession by General Assembly resolution 2200 A (XXI) of 16 December 1966.*

Entry into force: 23 March 1976, in accordance with Article 49.

#### **Article 6**

1. Every Human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

### **IV. International Convention on the Elimination of all Forms of Racial Discrimination (ICEFRD)**

*Adopted and opened for signatures and ratification by General Assembly resolution 2106 A (XX) of 21 December 1965.*

Entry into force: 4 January 1969, in accordance with Article 19.

#### **Article 5**

In compliance with the fundamental obligations laid down in article 2 of this Convention, States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights:

- (a) The right to equal treatment before the tribunals and all other organs administering justice.
- (b) The right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution.
- (c) Political rights, in particular the right to participate in elections-to vote and to stand for election-on the basis of universal and equal suffrage, to take part in the Government as well as in the conduct of public affairs at any level and to have equal access to public service.
- (d) Other civil rights, in particular:
  - (i) The right to freedom of movement and residence within the border of the State.
  - (ii) The right to leave any country, including one's own, and to return to one's country.
  - (iii) The right to nationality.
  - (iv) The right to marriage and choice of spouse.
  - (v) The right to own property alone as well as in association with others.

- (vi) The right to inherit.
- (vii) The right to freedom of thought, conscience and religion.
- (viii) The right to freedom of opinion and expression.
- (ix) The right to freedom of peaceful assembly and association.
- e) Economic, social and cultural rights, in particular:
  - i) The rights to work, to free choice of employment, to just and favorable conditions of work.
  - ii) Right to form and join trade unions.
  - iii) The right to housing.
  - iv) The right to public health, medical care, social security and social services.
  - v) The right to education and training.
  - vi) The right to equal participation in cultural activities.
- f) The right of access to any place or service intended for use by the general public, such as transport hotels, restaurants, cafes, theatres and parks.

## V. The United Nations Convention on the Rights of the Child (CRC)

*Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989.*

Entry into force: 2 September 1990, in accordance with article 49.

### **Article 24**

1. States Parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such healthcare services.
2. States Parties shall pursue full implementation of this right and in particular, shall take appropriate measures:
  - a) To diminish infant and child mortality.
  - b) To ensure the provision of necessary medical assistance and healthcare to all children with emphasis on the development of primary healthcare.
  - c) To combat disease and malnutrition, including within the framework of primary healthcare, through, inter alia, the application of readily available technology and through the provision of adequate nutritious food and clean drinking water, taking into consideration the dangers and risks of environmental pollution.
  - d) To ensure appropriate pre-natal healthcare for mothers.
  - e) To ensure that all segments of society, in particular parents and children are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breast-feeding, hygiene and environmental sanitation and the prevention of accidents.

- f) To develop preventive healthcare, guidance for parents and family planning education and services.
3. States Parties shall take effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.
4. States Parties undertake to promote and encourage international co-operatives with a view to achieving progressively the full realisation of the right recognised in the present Article. In this regard, particular account shall be taken of the needs of developing countries.

## **VI. Convention on the Elimination of all forms of Discrimination Against Women (CEDAW)**

*Adopted and opened for signature, ratification and accession by General Assembly resolution 34/180 of 18 December 1979.*

Entry into force: 3 September 1981, in accordance with Article 27 (1).

### **Article 12**

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of healthcare in order to ensure, on a basis of equality of men and women, access to healthcare services, including those related to family planning.
2. Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

### **Article 14**

1. States Parties shall take into account the particular problems faced by rural women and the significant roles which rural women play in the economic survival of their families, including their work in the non-monitored sectors in the economy, and shall take all appropriate measures to ensure the application of the provisions of this Convention to women in rural areas.
2. States Parties shall take all appropriate measures to eliminate discrimination against women in rural areas in order to ensure, on a basis of equality of men and women, that they participate in and benefit from rural development and in, particular, shall ensure to such women the right:
  - a) To participate in the elaboration and implementation of development planning at all levels.
  - b) To have access to adequate healthcare facilities, including information, counseling and services in family planning.
  - c) To enjoy adequate living conditions, particularly in relation to housing, sanitation, electricity and water supply, transport and communications.

## **VII. UN's principle for the Protection of Persons with Mental Illness and the improvement on Mental healthcare (UN Mental Health principles)**

The UN Mental Health Principles was adopted by the General Assembly in 1991. The focus of these 25 principles is on individuals receiving mental healthcare. Though these principles are not legally binding, they have influenced municipal law in some countries, such as the drafting of New Zealand's Mental Health (Compulsory Assessment and Treatment) Act 1992.

## **VIII. Conventions that address HIV/AIDS**

There is a wide range of human rights related UN treaties or conventions, as well as certain regional conventions; all these create obligations for those countries that have signed or ratified them. There is no international convention or treaty specifically addressing human rights and HIV/AIDS. However, many treaties and conventions contain human rights principles relevant to HIV/AIDS. These include for example, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child.

Internationally recognised human rights principles relevant to HIV/AIDS include the right to non-discrimination and equality before law, the right to life and to health, the right to information and to freedom of expression, the right to marry and raise a family, the right to work to an adequate living standard and to social security, the right to share in scientific advancement and its benefits etc.

—Article 2 of the ICCPR to which India is a party protects all persons from discrimination on the basis of “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.” This article has been widely interpreted by the UN Commission on Human Rights and other UN bodies to include both sexual orientation and HIV status as factors on the basis of which discrimination is prohibited.

—Article 9 of the ICCPR guarantees the right to “liberty and security of person” and to be free from “arbitrary arrest or detention.” The article further specifies that anyone arrested or detained on a criminal charge have a right to be brought promptly before a judge within a reasonable time.

Outreach workers are frequently subject to unlawful arrest and detention and mistreatment, including torture, in violation of international law.

—Article 19 of ICCPR guarantees the right to freedom of expression, including “freedom to seek, receive and impart information and ideas of all kinds.”

—Article 26 of the ICCPR guarantees equal protection of the law and non-discrimination before the law on

the same grounds as those noted in Article 2.

The ICCPR and the Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment, to which India is a signatory but not a party, both prohibit torture and cruel inhuman or degrading treatment or punishment, without exception or derogation. Although they do not have the force of international law, the United Nations Guidelines on HIV/AIDS and Human Rights are frequently used as a guide to policy and the law related to HIV/AIDS.

Internationally, the rights of children are enshrined in the CRC. It advocates the right of every child to complete and wholesome development and opportunity along with specific rights such as the right to family, education, health services, participation in decision-making, freedom of expression, freedom of association and the right against exploitation, trafficking and torture. Article 19 guarantees protection for all children against “all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation including sexual abuse.” In the context of sexual health education, the cornerstone of HIV/AIDS interventions, the Committee on the Rights of the Child under the CRC recommends that “access to information as a fundamental right of the child should become the key element in HIV/AIDS prevention strategies.” India is one of the few countries whose Constitution specifically recognises the rights of children. Article 15(3) of the Constitution enables the State to make special provisions for children. The International Guidelines of HIV/AIDS and Human Rights recommend that States “ensure that children and adolescents have adequate access to confidential sexual and reproductive health services, including HIV/AIDS information, counseling, testing and prevention measures such as condoms.”

## **United Nations General Assembly Special Session(UNGASS) on HIV/AIDS**

The Commission on Human Rights has recognised the issue of global access to medicines as one of the fundamental element for achieving progressively the full realisation of the right of everyone to the enjoyment of the highest attainable standard of health. These developments hold the potential for making a difference. In this context, it is important to discuss one of such developments, i.e. the outcomes of the UN General Assembly Special Session (UNGASS) on HIV/AIDS in June 2001.

At the end of June 2001, UN Member States unanimously adopted a Declaration of Commitment on HIV/AIDS in which they reiterated their recognition that access to medication in the context of pandemics such as HIV/AIDS is fundamental to realising the right to health (paragraph 15), and further recognised:

—That prevention, care, support and treatment for those infected and affected by HIV/AIDS are mutually reinforcing elements of an effective response and must be integrated in a comprehensive approach to combat the epidemic (paragraph 17).

—That care, support and treatment can contribute to effective HIV prevention (paragraph 19).

—That effective prevention, care and treatment strategies will require increased availability of, and non-discriminatory access to, inter alia drugs (including anti-retroviral therapy), diagnostics and related technologies (paragraph 23).

—That the cost, availability and affordability of drugs and related technology are significant factors to be reviewed and addressed in all aspects and that there is a need to reduce the cost of these drugs and technologies in close collaboration with the private sector and pharmaceutical companies (paragraph 24).

—That the lack of affordable pharmaceuticals and of feasible supply structures and health systems continues to hinder an effective response to HIV/AIDS in many countries, especially for the poorest people (paragraph 25).

The General Assembly further noted that the impact of international trade agreements on access to or local manufacturing of essential drugs and on the development of new drugs needs to be evaluated further (paragraph 26).

The UNGASS Declaration of Commitment, to which India is a signatory, commits India to make anti-retroviral available to PLWHAs. It mandates that States Parties:

“By 2003... in an urgent manner make every effort to provide progressively and in a sustainable manner, the highest attainable standard of treatment for HIV/AIDS, including the prevention and treatment of opportunistic infections, and effective use of quality controlled anti-retroviral therapy in a careful and monitored manner to improve adherence and effectiveness and reduce the risk of developing resistance.”

India is also committed to implementing universal precautions in healthcare settings to prevent the transmission of HIV and to reduce mother-to-child transmission. The Supreme Court of India has held that international instruments can be read to expand the fundamental rights guaranteed under the Constitution of India. Therefore, the UNGASS Declaration of Commitment can well be used to expand upon the right to health and cast an obligation on the State to provide ARVs to PLWHAs.

## Conference Documents

### **I. The International Conference on Population and Development Programme of Action (The ICPD Programme of Action)**

*Principle 1* Everyone has the right to life, liberty and security of person.

*Paragraph 7.3* ...[Reproductive rights] also includes [couples and individuals] right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents...

*Paragraph 7.17* Government at all levels are urged to institute systems of monitoring and evaluation of user-centered services with a view to detecting, preventing and controlling abuses by family-planning managers and providers ... To this end, Governments should secure conformity to human rights and to ethical and professional standards in the delivery of family planning and related reproductive health services aimed at ensuring responsible, voluntary and informed consent and also regarding service provision.

*Paragraph 8.34* Governments should develop policies and guidelines to protect the individual rights of ... persons infected with HIV and their families. Services to detect HIV infections should be strengthened, making sure that they ensure confidentiality.

*Paragraph 7.45* Recognizing the rights, duties and responsibilities of parents and other persons legally responsible for adolescents to provide, in a manner consistent with the evolving capacities of the adolescent, appropriate direction and guidance in sexual and reproductive matters, countries must ensure that the programmes and attitudes of healthcare providers do not restrict the access of adolescents to appropriate services and the information they need, including on sexually transmitted infections and sexual abuse.

*Principle 8* Everyone has right to the enjoyment of the highest attainable standard of physical and mental health. States should take all appropriate measures to ensure, on a basis of equality of men and women, universal access to healthcare services, including those related to reproductive healthcare, which includes family planning and sexual health. Reproductive healthcare programmes should provide the widest range of services without any form of coercion.

## **II. The Fourth World Conference on Women Platform for Action (The FWCW Platform)**

*Paragraph 89* Women have the right to the enjoyment of the highest attainable standard of physical and mental health. Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

*Paragraph 92* Women's right to the enjoyment of the highest standard of health must be secured throughout the whole life cycle in equality with men.

*Paragraph 96* The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence.

*Paragraph 106* Governments [should] ... (g) Ensure that all health services and workers conform to human rights and to ethical, professional and gender-sensitive standards in the delivery of women's health services aimed at ensuring responsible, voluntary and informed consent; encourage the development, implementation and dissemination of codes of medical ethics as well as ethical principles that govern other health professionals.

*Paragraph 108* Governments [should]...(c) Encourage all sectors of society ... to develop compassionate and supportive, non-discriminatory HIV/AIDS-related policies and practices that protect the rights of infected individuals.

### **III The World Conference on Human Rights (WCHR)**

*Paragraph 41* The World Conference on Human Rights recognises the importance of the enjoyment by women of the highest standard of physical and mental health throughout their life-span...The World Conference on Human Rights reaffirms, on the basis of equality between women and men, a woman's right to accessible and adequate healthcare and the widest range of family planning services, as well as equal access to education at all levels.

#### ***Vienna Declaration and Programme of Action***

(Adopted by the World Conference on Human Rights on 25 June 1993)

The human rights of women and of the girl-child are an inalienable, integral and indivisible part of universal human rights. The full and equal participation of women in the political, civil, economic, social and cultural life, at the national, regional and international levels, and eradication of all forms of discrimination on grounds of sex are priority objectives of the international community.

Gender-based violence and all forms of sexual harassment and exploitation, including those resulting from cultural prejudice and international trafficking are incompatible with the dignity and worth of the human person, and must be eliminated. This can be achieved by legal measures and through national action and international cooperation in such fields as economic and social development, education, safe maternity and healthcare, and social support.

The human rights of women should form an integral part of the United Nations human rights activities including the promotion of all human rights instruments relating to women.

The World Conference urges governments, institutions, intergovernmental and non-governmental organisations to intensify their efforts for the protection and promotion of human rights of women and the girl-child.

### **IV. World Health Organisation (WHO)-Declaration**

1. We, the Member States of the World Health Organisation (WHO), reaffirm our commitment to the principle enunciated in its Constitution that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being; in doing so, we affirm the dignity and worth of every person, and the equal rights, equal duties and shared responsibilities of all for health.

2. We recognise that the improvement of the health and well-being of people is the ultimate aim of social and economic development. We are committed to the ethical concepts of equality, solidarity and social justice and to the incorporation of a gender perspective into our strategies. We emphasize the importance of reducing social and economic inequities in improving the health of the whole population. Therefore, it is imperative to pay the greatest attention to those most in need, burdened by ill health, receiving inadequate services for health or affected by poverty. We reaffirm our will to promote health by addressing the basic determinates and prerequisites for health. We acknowledge that changes in the world health situation require that we give effect to the 'Health- for- All policy for the twenty- first century' through relevant regional and national policies and strategies.
3. We recommit ourselves to strengthening, adapting and reforming, as appropriate... our health systems are based on scientific evidence, of good quality and within affordable limits, and that are sustainable for the future. We intend to ensure the availability of the essentials of primary healthcare as defined in the Declaration of Alma-Ata and developed in the new policy. We will continue to develop health systems to respond to the current and anticipated health conditions, socio-economic circumstances and needs of the people, communities and countries concerned through appropriately managed public and private actions and investments for health.
4. We recognise that in working towards health for all, all nations, communities, families and individuals are interdependent. As a community of nations, we will act together to meet common threats to health and to promote universal well-being.
5. We, the Member States of the World Health Organisation, hereby resolve to promote and support the rights and principles, action and responsibilities enunciated in this Declaration through concerted action, full participation and partnership, calling on all peoples and institutions to share the vision of Health for All in the twenty-first century and to endeavor to realise it.

## Annexure II

# People's Health Charter

We the people of India, stand united in our condemnation of an iniquitous global system that, under the garb of “globalisation” seeks to heap unprecedented misery and destitution on the overwhelming majority of the people on this globe. This system has systematically ravaged the economies of poor nations in order to extract profits that nurture a handful of powerful nations and corporations. The poor, across the globe, are being further marginalised as they are displaced from home and hearth and alienated from their sources of livelihood as a result of the forces unleashed by this system. Standing in firm opposition to such a system we reaffirm our inalienable right to comprehensive healthcare that includes food security; sustainable livelihood options; access to housing, drinking water and sanitation; and appropriate medical care for all; in sum - the right to HEALTH FOR ALL, NOW!

The promises made to us by the international community in the Alma Ata declaration have been systematically repudiated by the World Bank, the IMF, the WTO and its predecessors, the World Health Organisation, and by a government that functions under the dictates of international Finance Capital. The forces of “globalisation” through measures such as the structural adjustment programme are targeting our resources - built up with our labour, sweat and lives over the last fifty years - and placing them in the service of the global “market” for extraction of super-profits. The benefits of the public sector healthcare institutions, the public distribution system and other infrastructure - such as they were - have been taken away from us. It is the ultimate irony that we are now blamed for our plight, with the argument that it is our numbers and our propensity to multiply that is responsible for our poverty and deprivation.

We declare health as a justiciable right and demand the provision of basic healthcare as a fundamental constitutional right of every one of us. We assert our right to take control of our health in our own hands and for this the right to:

- A truly decentralised system of local governance vested with adequate power and responsibilities and provided with adequate finances.
- A sustainable system of agriculture based on the principle of “land to the tiller”, linked to a decentralised public distribution system that ensures that no one goes hungry.
- Universal access to education, adequate and safe drinking water, and housing and sanitation facilities.
- A dignified and sustainable livelihood.
- A clean and sustainable environment.
- A drug industry geared to producing epidemiologically essential drugs at affordable cost.
- A healthcare system which is responsive to the people's needs and whose control is vested in peoples hands.

Further, we declare our firm opposition to:

- Agricultural policies attuned to the needs of the “market” that ignore disaggregated and equitable access to food.
- Destruction of our means to livelihood and appropriation, for private profit, of our natural resource bases.
- The conversion of Health to the mere provision of medical facilities and care that are technology intensive, expensive, and accessible to a select few.
- The retreat, by the government, from the principle of providing free medical care, through reduction of public sector expenditure on medical care and introduction of user fees in public sector medical institutions, that place an unacceptable burden on the poor.
- The corporatisation of medical care, state subsidies to the corporate sector in medical care, and corporate sector health insurance.
- Coercive population control and promotion of hazardous contraceptive technology.
- The use of patent regimes to steal our traditional knowledge and to put medical technology and drugs beyond our reach.
- Institutionalisation of divisive and oppressive forces in society, such as fundamentalism, caste, patriarchy, and the attendant violence, which have destroyed our peace and fragmented our solidarity.

In the light of the above, we demand that:

1. The concept of comprehensive primary healthcare, as envisioned in the Alma Ata Declaration should form the fundamental basis for formulation of all policies related to healthcare. The trend towards fragmentation of health delivery programmes through conduct of a number of vertical programmes should be reversed. National health programmes be integrated within the Primary Health Care system with decentralised planning, decision-making and implementation. Focus be shifted from bio-medical and individual based measures to social, ecological and community based measures.
2. The primary medical care institutions including trained village health workers, sub-centres, and the PHCs staffed by doctors and the entire range of community health functionaries be placed under the direct administrative and financial control of the relevant level panchayat raj institutions. The overall infrastructure of the primary healthcare institutions be under the control of panchayati raj and gram sabhas and provision of free and accessible secondary and tertiary level care be under the control of zilla parishads, to be accessed primarily through referrals from PHCs. The essential components of primary care should be:
  - Village level healthcare based on Village Health Workers selected by the community and supported by the Gram Sabha / Panchayat and the Government health services.
  - Primary Health Centers and subcentres with adequate staff and supplies which provide quality curative services at the PHC level itself with good support from linkages.
  - A comprehensive structure for primary healthcare in urban areas based on urban PHCs, health posts and Community Health Workers.
  - Enhanced content of primary healthcare to include all measures which can be provided at the PHC level even for less common or non-communicable diseases (e.g. epilepsy, hypertension, arthritis, pre-eclampsia, skin diseases) and integrated relevant epidemiological and preventive measures.

- Surveillance centres at block level to monitor the local epidemiological situation and tertiary care with all specialty services, available in every district.
3. A comprehensive medical care programme financed by the government to the extent of at least 5 percent of our GNP, of which at least half be disbursed to panchayati raj institutions (PRIs) to finance primary level care. This be accompanied by transfer of responsibilities to PRIs to run major parts of such a programme, along with measures to enhance capacities of PRIs to undertake the tasks involved.
  4. The policy of gradual privatisation of government medical institutions, through mechanisms such as introduction of user fees even for the poor, allowing private practice by Government doctors, giving out PHCs on contract, etc. be abandoned forthwith. Failure to provide appropriate medical care to a citizen by public healthcare institutions be made punishable by law.
  5. A comprehensive need-based human power plan for the health sector be formulated that addresses the requirement for creation of a much larger pool of paramedical functionaries and basic doctors, in place of the present trend towards over-production of personnel trained in super-specialties. Major portions of undergraduate medical education, nursing as well as other paramedical training be imparted in district level medical care institutions, as a necessary complement to training provided in medical/nursing colleges and other training institutions. No more new medical colleges to be opened in the private sector. Steps be taken forthwith to close down private medical colleges charging fees higher than state colleges or taking any form of donations, and to eliminate illegal private tuition by teachers in medical colleges. At least a year of compulsory rural posting for undergraduate (medical, nursing and paramedical) education be made mandatory, without which license to practice not be issued. Similarly, three years of rural posting after post graduation be made compulsory.
  6. The unbridled and unchecked growth of the commercial private sector be brought to a halt. Strict observance of standard guidelines for medical and surgical intervention and use of diagnostics, standard fee structure, and periodic prescription audit to be made obligatory. Legal and social mechanisms be set up to ensure observance of minimum standards by all private hospitals, nursing/maternity homes and medical laboratories. Prevalent practice of offering commissions for referral to be made punishable by law. For this purpose a body with statutory powers be constituted, which has due representation from peoples' organisations and professional organisations.
  7. A rational drug policy be formulated that ensures development and growth of a self-reliant industry for production of all essential drugs at affordable prices and of proper quality. The policy should, on a priority basis:
    - Ban all irrational and hazardous drugs.
    - Introduce production quotas and price ceiling for essential drugs.
    - Promote compulsory use of generic names.
    - Regulate advertisements, promotion and marketing of all medications based on ethical criteria.
    - Formulate guidelines for use of old and new vaccines.
    - Control the activities of the multinational sector and restrict their presence only to areas where they are willing to bring in new technology.
    - Recommend repeal of the new patent act and bring back mechanisms that prevent creation of monopolies and promote introduction of new drugs at affordable prices.

- Promotion of the public sector in production of drugs and medical supplies, moving towards complete self-reliance in these areas.
8. Medical research priorities be based on morbidity and mortality profile of the country, and details regarding the direction, intent and focus of all research programmes be made entirely transparent. Adequate government funding be provided for such programmes. Ethical guidelines for research involving human subjects be drawn up and implemented after an open public debate. No further experimentation, involving human subjects, be allowed without a proper and legally tenable informed consent and appropriate legal protection. Failure to do so, to be punishable by law. All unethical research, especially in the area of contraceptive research, be stopped forthwith. Women (and men) who, without their consent and knowledge, have been subjected to experimentation, especially with hazardous contraceptive technologies to be traced forthwith and appropriately compensated. Exemplary damages to be awarded against the institutions (public and private sector) involved in such anti-people, unethical and illegal practices in the past.
  9. All coercive measures including incentives and disincentives for limiting family size be abolished. The right of families and women within families in determining the number of children they want should be recognised. Concurrently, access to safe and affordable contraceptive measures be ensured which provides people, especially women, the ability to make an informed choice. All long-term, invasive, systemic hazardous contraceptive technologies such as the injectables (NET-EN, Depo-Provera, etc.), sub-dermal implants (Norplant) and anti fertility vaccines should be banned from both the public and private sector. Urgent measure be initiated to shift the onus of contraception away from women and ensure at least equal emphasis on men's responsibility for contraception.
  10. Support be provided to traditional healing systems, including local and home-based healing traditions, for systematic research and community-based evaluation with a view to developing the knowledge base and use of these systems along with modern medicine as part of a holistic healing perspective.
  11. Promotion of transparency and decentralisation in the decision-making process, related to healthcare, at all levels as well as adherence to the principle of right to information. Changes in health policies to be made only after mandatory wider scientific public debate.
  12. Introduction of ecological and social measures to check resurgence of communicable diseases. Such measures should include:
    - Integration of health impact assessment into all development projects.
    - Decentralised and effective surveillance and compulsory notification of prevalent diseases like malaria, TB by all healthcare providers, including private practitioners.
    - Reorientation of measures to check STIs, HIV /AIDS through universal sex education, checking social disruption and displacement and commercialisation of sex, generating public awareness to remove stigma and universal availability of preventive and curative services, and special attention to empowering women and availability of gender sensitive services in this regard.
  13. Facilities for early detection and treatment of non-communicable diseases like diabetes, cancers, heart diseases, etc., to be available to all at appropriate levels of medical care.
  14. Women-centered health initiatives that include:
    - Awareness generation for social change on issues of gender and health, triple work burden, gender

discrimination in nutrition and healthcare.

- Preventive and curative measures to deal with health consequences of women's work and domestic violence.
  - Complete maternity benefits and childcare facilities to be provided in all occupations employing women, be they in the organised or unorganised sector.
  - Special support structures that focus on single, deserted, widowed women and commercial sex workers; gender sensitive services to deal with reproductive health including reproductive system illnesses, maternal health, abortion, and infertility.
  - Vigorous public campaign accompanied by legal and administrative action against female foeticide, infanticide and sex pre-selection.
15. Child centered health initiatives, which include:
- A comprehensive child rights code, adequate budgetary allocation for universalisation of childcare services, an expanded and revitalised ICDS programme and ensuring adequate support to working women to facilitate childcare, especially breast feeding.
  - Comprehensive measures to prevent child abuse and sexual abuse.
  - Educational, economic and legal measures to eradicate child labour, accompanied by measures to ensure free and compulsory elementary education for all children.
16. Special measures relating to occupational and environmental health which focus on:
- Banning of hazardous technologies in industry and agriculture.
  - Worker centered monitoring of working conditions with the onus of ensuring a safe workplace on the management.
  - Reorientation of medical services for early detection of occupational disease.
  - Special measures to reduce the likelihood of accidents and injuries in different settings, such as traffic accidents, industrial accidents, agricultural injuries, etc.
17. Measures towards mental health that promotes a shift away from a bio-medical model towards a holistic model of mental health. Community support and community-based management of mental health problems be promoted. Services for early detection and integrated management of mental health problems be integrated with primary healthcare.
18. Measures to promote the health of the elderly by ensuring economic security, opportunities for appropriate employment, sensitive healthcare facilities and, when necessary, shelter for the elderly.
19. Measures to promote the health of physically and mentally disadvantaged by focusing on the abilities rather than deficiencies. Promotion of measures to integrate them in the community with special support rather than segregating them; ensuring equitable opportunities for education, employment and special healthcare including rehabilitative measures.
20. Effective restriction on industries that promote addictions and an unhealthy lifestyle, like tobacco, alcohol, pan masala etc., starting with an immediate ban on advertising and sale of their products to the young, and provision of services for de-addiction.

## ANNEXURE 3

# National public hearing on Right to Healthcare

Organised by NHRC & JSA on 16-17 December 2004, New Delhi

Recommendations for a National Action Plan (Draft) to operationalise the Right to Healthcare within the broader framework of the Right to Health.

### Objectives of the National Action Plan

- **Explicit recognition of the Right to Healthcare**, to be enjoyed by all citizens of India, by various concerned parties: Union and State Government, NHRC, SHRCs and civil society and other health sector civil society platforms.
- **Delineation of essential health services and supplies** whose timely delivery would be assured as a right at various levels of the Public Health System.
- **Delineation of citizen's health rights related to the private medical sector** including a Charter of Patients' Rights.
- **Legal enshrinement of the Right to Healthcare** by enacting a Public Health Services Act, Public Health Services Rules and a Clinical Establishment Regulation Act to regulate the private medical sector.
- **Operationalisation of the Right to Healthcare** by formulation of a broad timetable of activities by the Union and State Governments, consisting of the essential steps required to ensure availability and accessibility of quality health services to all citizens, which would be necessary to operationalise the Right to Healthcare. This may include a basic set of Health Sector Reform measures essential for universal and equitable access to quality healthcare, and guidelines regarding the budgetary provisions to be made available for effective operationalisation.
- **Initiation of mechanisms for joint monitoring** at district, state and national levels involving Health departments and civil society representatives with specified regularity of monitoring meetings and powers to monitoring committee. Parallel to this, an institutionalised space needs to be created for regular civil society inputs towards a more consultative planning process. These should be combined with vigilance mechanisms to take prompt action regarding illegal charging of patients, unauthorised private practice, corruption relating to drugs and supplies etc.
- **Functional redressal mechanisms** to be put in place at district, state and national levels to address all complaints of denial of healthcare.

### Recommendations under the action plan

#### Recommendations to Government of India / Union Health Ministry

- **Enactment of a National Public Health Services Act recognising and delineating the Health Rights of citizens**, duties of the Public Health System, public health obligations of private healthcare providers and specifying broad legal and organisational mechanisms to operationalise

these rights. This act would make mandatory many of the recommendations laid down, and would make more justiciable the denial of healthcare arising from systemic failures as have been witnessed during the recent public hearings. This act would also include **special sections to recognise and legally protect the health rights of various sections of the populations which have special health needs**: Women, children, persons affected by HIV/AIDS, persons with mental health problems, persons with disability, persons in conflict situations, persons facing displacement, workers in various hazardous occupations including unorganised and migrant workers etc.

- **Delineation of model lists of essential health service at various levels**: village / community, sub-centre, PHC, CHC, Sub-divisional and District hospital to be made available as a right to all citizens.
- **Substantial increase in central budgetary provisions for Public health**, to be increased to 2--3% of the GDP by 2009 as per the Common Minimum Programme.
- **Convening one or more meetings of the Central Council on Health** to evolve a consensus among various state governments towards operationalising the Right to Healthcare across the country.
- **Enacting a National Clinical Establishments Regulation Act** to ensure **citizens' health rights concerning the private medical sector**, including right to emergency services; ensuring minimum standards, adherence to standard treatment protocols and ceilings on prices of essential health services. Issuing a Health Services Price Control Order parallel to the Drug Price Control Order; formulation of a Charter of Patients' Rights.
- **Setting up a Health services Regulatory Authority** - analogous to the Telecom regulatory authority - which broadly defines and sanctions what constitutes rational and ethical practice, and sets and monitors quality standards and prices of services. This is distinct and superior compared to the Indian Medical Council in that it is not representative of professional doctors alone - but includes representatives of legal healthcare providers, public health expertise, legal expertise, representatives of consumers, health and human rights groups and elected public representatives. Also this could independently monitor and intervene in an effective manner.
- **Issuing National Operational Guidelines on Essential Drugs** specifying the right of all citizens to be able to access good quality essential drugs at all levels in the Public Health System; promotion of generic drugs in preference to brand names; inclusion of all essential drugs under Drug Price Control Order; elimination of irrational formulations and combinations. Government of India should take steps to publish a National Drug Formulary based on the morbidity pattern of the Indian people and also on the essential drug list.
- **Measures to integrate National Health Programmes with the Primary Healthcare system** with decentralised planning, decision-making and implementation. Focus to be shifted from bio-medical and individual based measures to social, ecological and community based measures. Such measures would include compulsory health impact assessment for all development projects; decentralised and effective surveillance and compulsory notification of prevalent diseases by all healthcare providers, including private practitioners.
- **Reversal of all coercive population control measures** that are violative of basic human rights, have been shown to be less effective in stabilising population, and draw away significant resources and energies of the health system from public health priorities. In keeping with the spirit of the NPP 2000, steps need to be taken to eliminate and prevent all forms of coercive population control measures and the two-child norm, which targets the most vulnerable sections of society.

- Active participation by Union Health Ministry in a National mechanism for health services monitoring, consisting of a **Central Health Services Monitoring and Consultative Committee** to periodically review the implementation of health rights related to actions by the Union Government. This would also include deliberations on the underlying structural and policy issues, responsible for health rights violations. Half of the members of this Committee would be drawn from National level health sector civil society platforms. NHRC would facilitate this committee. Similarly, operationalising **Sectoral Health Services Monitoring Committees** dealing with specific health rights issues (Women's health, Children's health, Mental health, Right to essential drugs, Health rights related to HIV/AIDS etc.)
- The structure and functioning of the **Medical Council of India** should be immediately reviewed to make its functioning more democratic and transparent. Members from Civil Society Organisations concerned with health issues should also be included in the Medical Council.
- People's access to emergency medical care is an important facet of right to health. Based on the Report of the Expert Group constituted by NHRC (Dr. P.K. Dave Committee), short-term and long-term recommendations were sent to the Centre and to all States in May 2004. In particular, the Commission recommended:
  - I. Enunciation of a National Accident Policy.
  - II. Establishment of a central coordinating, facilitating, monitoring and controlling committee for Emergency Medical Services (EMS) under the aegis of Ministry of Health and Family Welfare as advocated in the National Accident Policy.
  - III. Establishment of Centralised Accident and Trauma Services in all districts of all States and various Union Territories along with strengthening infrastructure, pre-hospital care at all government and private hospitals.
- Spurious drugs and sub-standard medical devices have grave implications for the enjoyment of human rights by the people. Keeping this in view, all authorities are urged to take concrete steps to eliminate them.
- Access to Mental healthcare has emerged as a serious concern. The NHRC reiterates its earlier recommendations based on a study "Quality Assurance in Mental Health" which were sent to concerned authorities in the Centre and in States and underlines the need to take further action in this regard.

#### **Recommendations to State Government / State Health Ministries**

- **Enactment of State Public Health Services Rules** detailing and operationalising the National Public Health Services Act, recognising and delineating the Health rights of citizens, duties of the Public Health System and private healthcare providers and specifying broad legal and organisational mechanisms to operationalise these rights. This would include **delineation of lists of essential health services at all levels**: village/ community, sub-center, PHC, CHC, Sub-divisional and District hospital to be made available as a right to all citizens. This would take as a base minimum the National Lists of essential services mentioned above, but would be modified in keeping with the specific health situation in each state. These rules would also include **special sections to recognise and protect the health rights of various sections of the population which have special health needs**: Women, children, persons affected by HIV/AIDS, persons with mental health problems, persons in conflict situations, persons facing displacement, workers in various hazardous occupations including unorganised and migrant workers etc.

- Enacting **State Clinical Establishments Rules** regarding **health rights concerning the private medical sector**, detailing the provisions made in the National Act.
- **Enactment of State Public Health Protection Acts** that define the norms for nutritional security, drinking water quality, sanitary facilities and other key determinants of health. Such acts would complement the existing acts regarding environmental protection, working conditions etc. to ensure that citizens enjoy the full range of conditions necessary for health, along with the right to accessible, good quality health services.
- **Substantial increase in State budgetary provisions for Public Health** to parallel the budgetary increase at Central level, this would entail at least doubling of state health budget in real terms by 2009.
- **Operationalising a State level health services monitoring mechanism**, consisting of a **State Health Services Monitoring and Consultative Committee** to periodically review the implementation of health rights, and underlying policy and structural issues in the State. Half of the members of this Committee would be drawn from State level health sector civil society platforms. Corresponding **Monitoring and Consultative committees** with civil society involvement would be formed in all districts, and to monitor urban health services in all class A and class B cities.
- **Instituting a Health Rights Redressal Mechanism** at State and District levels, to enquire and take action relating to all cases of denial of healthcare within a specified time frame.
- **Public Health Sector Reform measures** to ensure health rights through strengthening public health systems, and making private care more accountable and equitable. The minimum aspects of a health sector reform framework that would strengthen public rights. **An illustrative list of such measures is as follows:**
  1. State Governments should take steps to **decentralise the health services** by giving control to the respective Panchyati Raj Institutions (PRIs) concerning the government hospitals up to the district level. Enough funds from the plan and non plan amount should be devolved to the PRIs at various levels. The local bodies should be given the responsibility to formulate and implement health projects within the overall framework of the health policy of the state. The elected representatives of the PRIs and the officers should be given adequate training in local level health planning. Integration between the health department and local bodies should be ensured in formulating and implementing the health projects at local levels.
  2. The adoption of a **State essential drug policy** that ensures full availability of essential drugs in the public health system. This would be through adoption of a graded essential drug list, transparent drug procurement and efficient drug distribution mechanisms and adequate budgetary outlay. The drug policy should also promote rational drug use in the private sector.
  3. The health department should prepare a **State Drug Formulary** based on the health status of the people of the state. The drug formulary should be supplied free of cost to all government hospitals and at subsidised rates to the private hospitals. Regular updating of the formulary should be ensured. Treatment protocols for common diseases should be prepared and made available to the members of the medical profession.
  4. The adoption of a **Universal Community Health Worker Programme** with adequate provisioning and support, so as to reach out to the weakest rural and urban sections, providing basic primary care and strengthening community level mechanisms for preventive, promotive, and curative care.

5. The adoption of a detailed plan with milestones, demonstrating how **essential secondary care services**, including emergency care services, which constitute a basic right but are not available today, would be made universally available.
6. The public **notification of medically underserved areas** combined with special packages administered by the local elected bodies to close these gaps in a time bound manner.
7. The adoption of an **integrated human resource development plan** to ensure adequate availability of health, human power at all levels.
8. The adoption of transparent **non-discriminatory workforce management policies**, especially on transfers and postings, so that medical personnel are available for working in rural areas and so the specialists are prioritised for serving in secondary care facilities according to public interest.
9. The adoption of **improved vigilance mechanisms** to respond to and limit corruption, negligence and different forms of harassment within both the public and private health system.
- Ensuring the implementation of the Supreme Court order regarding **food security, universalising ICDS programmes and mid day school meal programmes**, to address food insecurity and malnutrition, which are a major cause of ill-health.

#### **Recommendations to NHRC**

- NHRC would oversee the monitoring of health rights at the National level by initiating and facilitating the Central Health Service Monitoring Committee and at regional level by appointing Special Rapporteurs on Health Rights for all regions of the country.
- Review of all laws/ statutes relating to public health from a human rights perspective and to make appropriate recommendations to the Government for bringing out suitable amendments.

#### **Recommendations to SHRCs**

- SHRCs in each state would facilitate the State Health Rights Monitoring Committee and oversee the functioning of the State level health rights redressal mechanisms.

#### **Recommendations to Jan Swasthya Abhiyan and civil society organisations**

- JSA and various civil society organizations would work for the widest possible raising of awareness on health rights - "Health Rights Literacy" among all sections of citizens of the country.

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