The Right to Health Care is a Basic Human Right!

Towards attaining the Right to health care...

The Government of India has been unable to fulfill it's commitment of 'Health for All by 2000 A.D.' till now. In fact, primary health care services are becoming more and more difficult to obtain for people living especially in urban slums, villages or remote tribal regions. The condition of government hospitals is worsening day by day. Nowadays, in most of the Government hospitals there is inadequate staff, the supply of medicines is insufficient and the infrastructure is also inadequate. There are very inadequate facilities for safe deliveries or abortions in Govt. hospitals. Given the fact that women do not even get adequate treatment for minor illnesses such as anaemia, services for problems such as the health effects of domestic violence remain almost completely unavailable. At the village level, there is no resident health care provider to treat illnesses or implement preventive measures. All hospitals are located in big cities, and here too public hospitals are increasingly starved of funds and facilities. Thus there is lack of availability of government health care services on one hand and the exorbitant cost of private health services on the other. This often leaves common people in rural areas with no other option but to resort to treatment from quack doctors who often practice irrationally. Thus most of the population is being deprived of the basic right to health care, which is essential for healthy living.

The Indian Constitution has granted the 'Right to Life' as a basic human right to every citizen of India under article 21. In article 47 of the Directive Principles of the Indian Constitution, the Government's responsibility concerning public health has also been laid down. Yet the Government is backtracking from fulfilling this responsibility. This is obvious from the fact that the Governments proportion of expenditure on public health services has been declining in successive years.

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• We can document case studies of 'denial of health care' in our areas. This process has already started in Maharashtra. Information is being collected in a specific format with the help of a questionnaire. The cases where denial of health services has led to the loss of life, physical damage or severe financial loss of the patient are being emphasised. These case studies would be presented to the National Human Rights Commission. These case studies would help us to depict the real status of provision of the primary health services by the government, would strengthen our demand for improving public health services and would help us in dialoguing with the public health system.

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Protocol to document cases of Denial of Right to Health Care

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Some of the major types of cases of this kind are outlined below, however any other similar cases, which come to the attention of activists, can be documented.

Some types of cases of denial of Right to Health Care

(This is not an exhaustive list but rather outlines certain broad categories with examples)

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Some guidelines for activists documenting the case studies.

- At least two case studies should be collected from each district / by each organisation. The attempt should be to document cases where denial of health care has resulted in significant loss to the patient, either in physical or financial terms, to strengthen the case for a human rights violation. Document only those case studies where incidence of denial has taken place in the last 6 months. Collect at least half of the case studies concerning women who have been denied health care. Any case papers / prescriptions or other relevant documents should be collected as supportive documents.
- Take oral consent of the person from whom the information will be elicited. Give that person
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Primary Health Center/ Govt. Hospital Services - Survey Questionnaire

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Date of interview - Name of Respondent (if different from potient)
Details of care received a	t PHC / Hospital

- ◆ Location of the PHC / Location and type of Hospital —
- Illness / complaints for which PHC / Hospital was visited -
- ♦ Total Number of visits to PHC / Hospital for this illness -
- ◆ Date of last visit –

Name of patient-

1. History of last visit in the patients / attendants words -

(Here we want to collect information regarding the main symptoms of the patient, who gave care and what kinds of examination, investigation and treatment were given)

 What were the perceived shortcomings or deficiencies in care? (As perceived by the patient or attendants)

According to patient, was there any adverse outcome because of deficient care? (Death, disability, continued or chronic health problem, severe financial loss e.g. major loan or sale of assets)

2. Medical attention received:

Name of the doctor who attended to you -

If the doctor was not available at that time, then who attended to you -

- 1. Nurse / ANM
- 2. MPW
- 3. Pharmacist
- 4. Any other person, specify
- How long after you reached the PHC / Hospital did the Medical Officer / Doctor attend toyou?
- Was examination / treatment / operation delayed or denied because of non-availability of a nurse, doctor or specialist?

- ♦ In case of an emergency did the doctor immediately attend to the patient? During hospital stay, regarding conditions that required immediate care, was the doctor available to immediately attend to the patient?
- Were nurses or hospital staff available to attend to the patient as and when required?
- Do you think that non-availability of any crucial equipment or supply (oxygen, incubator, anaesthetic equipment, blood, emergency drugs etc.) adversely affected the quality of care?
- Were all the equipments required for the examination and treatment of the patient available in working condition in the hospital?

Diagnosis- (as told by the doctor)

3. Medicines:

- Did you get all the required medicines at the PHC / Hospital?
- Did you have to go to any private medical shop to buy some medicines?
- ♦ If so, which medicines you had to buy from private medical shop?
- How much did it cost?
- Do you have the prescription?

4. Expenditure:

- ♦ Case paper / card made yes/no
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- · fees | charges for other services:

- Did you receive a receipt for the payment made?
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- Did your family have to sell assets (land, cattle, jewelry etc.) or take loans to pay for treatment in the Govt. hospital?

5. Referral:

- Was the patient refused admission or referred to another hospital without giving first aid care?
- If the patient was referred, was ambulance or other vehicle made available for the same?
- Did the Govt. doctor ask you to avail of any private services (e.g. laboratory services, Sonography / X ray) while you were admitted in the Govt. hospital?
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VELONETO PRESENTATION UNIVERSAL ACCESS TO HEALTH CARE

OTAL DIAMOND JUBILEE MEETING, UMDERABAD, 25TH OOTOBER 2003 UMMERSALAXBOESS

- I. Historical Background: India Bhore Committee Report 1948 - Comprehensive Health Care
 - unfulfilled promises from medical developments
 - Experimentation and pressure from voluntary sector 1960s, 1970s
 - WHO- UNICEF led Alma Ata Conference 1978.

- Primary Health Care to achieve Health for All by 2000
- · Signed by 134 countries, including India
- · A sociopolitical health approach
- Equitable, appropriate, affordable response to basic health care needs.

NIVERSAL ACCESS TO HEALTH CARE - POLICY ASPECTS

II. Primary Health Gare Principles

- Universal access and coverage on basis of need.
- Comprehensive care especially on health promotion and disease prevention water and sanitation, nutrition, MCH, FP, essential drugs, basic curative care, control of epidemic diseases.
- Community and individual involvement.
- Self reliance
- Intersectoral Action for Health.
- Appropriate technology.
- Cost effectiveness Social justice and equity were basic values and recognition of the right to health and health care.

BRIWARY REALTH GARG

Held the promise of better health, where health is not the absence of disease, but a state of well-being physical, mental, social, and spiritual

This implied-

a role for the state; - a role for different systems of medicine and healing. individual responsibility;

role for families / households and communities / civil society, NGOs

UNIVERSAL ACCESS TO HEALTH CARE - POLICY ASPECT

It implies

- decisions regarding resource allocations and strategies.
- prioritization and choices.
- health system development
- developing human resources for health

MINDIA-KATIOKALIHENTHEOTOY 1028

reflected and developed on the Alma Ata Declaration

However

- a) financial resource allocation to health and its distribution to primary health care was insufficient.
- b) vertical programmes continued.
- c) medical care aspects received greater focus eg. Immunization,EP
- d) expansion of infrastructure and personnel took place.
- e) implementation was not closely followed.

UNIVERSAL ACCESS TO HEALTH CARE - POLICY ASPECTS

V.From Mid 1980s

Growth of the private sector accelerated in health care provision, drug production, medical education.

The World Bank entered the health policy arena

 the largest financier of health programmes.



Used loan leverage to affect health policy.

Private sector development / privatization further strengthened

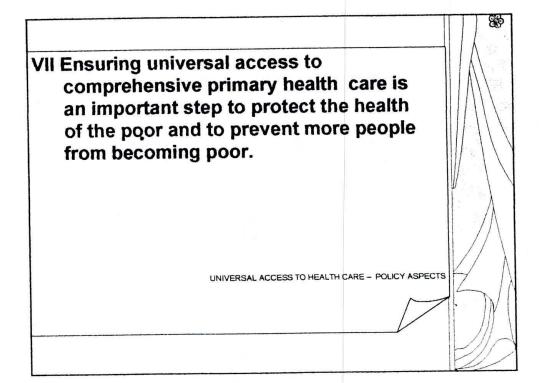
- Commercialization of health care.

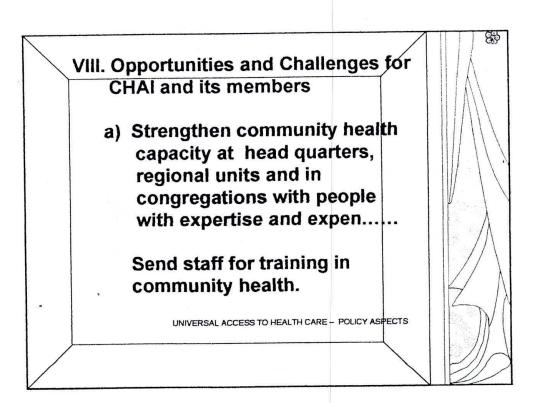
Entry of corporate sector and of multinationals
WTO – TRIPS - GATS
Rising drug prices and cost of care

UNIVERSAL ACCESS TO HEALTH CARE - POLICY ASPECTS

VI Past few years - fall in prices of primary

 $\hat{\parallel}$ rival poverty and distress.





- (b) Develop working links with different departments of government at local, district, state and national level. Be Present and contribute to policy making bodies.
- (c) Do not work in isolation network more actively.
- (d) Participate and strengthen the Jan Swasthya Abhiyan at village / slum and state / national level.

UNIVERSAL ACCESS TO HEALTH CARE - POLICY ASPECTS

e)Build on strengths of CHAI

- love for and working with the poor
- > Women's health
- ➤ Indian and other systems of medicine.
- Good quality training of nurses and other health personnel
- Rational therapeutics, hospital formalities.
- > Value base and professional ethics.
- > Health Action as a medium of communication

f) Help to place health on people's and politica	ı /
agenda.	
g) Involve communities / people in running the hea	alth institutions and their
heath care.	
h) Shift	
Curative comprehensive health care.	
Patients partners in health and healing	
dependency	
providing facilitating, using all resource	S
doctors disease diagnostics drugs positive	e health, healing
relationships holding brokenness.	
health care determinants of health	
institution => community / people	g.
medical approach - societal approach, societal	al analysis.
UNIVERSAL ACCESS TO HEALTH CA	ARE - POLICY ASPECTS
	,

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These are some of the steps being planned to move towards establishing the Right to health care. Let us join this campaign and strengthen the movement to achieve health care and health for all!

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Protocol to document cases of Denial of Right to Health Care

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Some of the major types of cases of this kind are outlined below, however any other similar cases, which come to the attention of activists, can be documented.

Some types of cases of denial of Right to Health Care

(This is not an exhaustive list but rather outlines certain broad categories with examples)

A. General Emergencies: Cases where a patient with a serious medical problem has been taken to a Govt. health centre or hospital (PHC / Rural / Cottage / Sub-divisional / District Hospital) and has been denied the life-saving or stabilising services expected at that facility. The patient may have unnecessarily been referred to a higher facility, leading to delay in treatment and serious adverse consequences, including death. Examples may include non-availability of:

- In a PHC Non-availability of treatment for snakebite or Anti-rabies vaccine; Non-availability of treatment for a child with pneumonia or severe dehydration due to diarrhea resulting in death
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- Care for burns: A woman reporting with burns in a Rural hospital or higher facility and not receiving care for burns
- C. Major chronic illnesses: Any facility, PHC or above not regularly giving full range of medication to patients with T.B. leading to deterioration of the patients condition including death; Sub-divisional hospital or higher facility not treating/admitting a case of AIDS
- D. Outbreak of immunisable or other major preventable illness such as measles, cholera, epidemic hepatitis or malaria due to failure of basic preventive or public health measures.
- E. Mental Illnesses Patients who have been denied health care for mental illness in a CHC or higher facility

Some guidelines for activists documenting the case studies.

- At least two case studies should be collected from each district / by each organisation. The
 attempt should be to document cases where denial of health care has resulted in significant loss to
 the patient, either in physical or financial terms, to strengthen the case for a human rights
 violation. Document only those case studies where incidence of denial has taken place in the last 6
 months. Collect at least half of the case studies concerning women who have been denied health
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Primary Health Center/ Govt. Hospital Services - Survey Questionnaire

Name of patient-		.e	
Age-			
Sex-			
Address-	C		
Date of interview - Name of Respondent (if	differen	nt from	patient)

Details of care received at PHC / Hospital

- ◆ Location of the PHC / Location and type of Hospital –
- Illness / complaints for which PHC / Hospital was visited -
- ♦ Total Number of visits to PHC / Hospital for this illness -
- ◆ Date of last visit –

1. History of last visit in the patients / attendants words -

(Here we want to collect information regarding the main symptoms of the patient, who gave care and what kinds of examination, investigation and treatment were given)

 What were the perceived shortcomings or deficiencies in care? (As perceived by the patient or attendants)

According to patient, was there any adverse outcome because of deficient care? (Death, disability, continued or chronic health problem, severe financial loss e.g. major loan or sale of assets)

2. Medical attention received:

Name of the doctor who attended to you −

If the doctor was not available at that time, then who attended to you -

- 1. Nurse / ANM
- 2. MPW
- 3. Pharmacist
- 4. Any other person, specify
- How long after you reached the PHC / Hospital did the Medical Officer / Doctor attend to ينعير.
- Was examination / treatment / operation delayed or denied because of non-availability of a nurse, doctor or specialist?

- In case of an emergency did the doctor immediately attend to the patient? During hospital stay, regarding conditions that required immediate care, was the doctor available to immediately attend to the patient?
- Were nurses or hospital staff available to attend to the patient as and when required?
- Do you think that non-availability of any crucial equipment or supply (oxygen, incubator, anaesthetic equipment, blood, emergency drugs etc.) adversely affected the quality of care?
- Were all the equipments required for the examination and treatment of the patient available in working condition in the hospital?

Diagnosis- (as told by the doctor)

3. Medicines:

- Did you get all the required medicines at the PHC / Hospital?
- Did you have to go to any private medical shop to buy some medicines?
- ♦ If so, which medicines you had to buy from private medical shop?
- How much did it cost?
- Do you have the prescription?

4. Expenditure:

- Case paper / card made yes/no
- Case paper fee / indoor fees charged
- · Fees | charges for other services:

- Did you receive a receipt for the payment made?
- Were you charged excess money at the PHC / Hospital (more than specified rates)?
- If yes, how much excess was charged?
- Did your family have to sell assets (land, cattle, jewelry etc.) or take loans to pay for treatment in the Govt. hospital?

5. Referral:

- Was the patient refused admission or referred to another hospital without giving first aid care?
- If the patient was referred, was ambulance or other vehicle made available for the same?
- Did the Govt. doctor ask you to avail of any private services (e.g. laboratory services, Sonography / X ray) while you were admitted in the Govt. hospital?
- In case you had to take the patient to a private hospital, which hospital? (name and address of the hospital)
- What was the total expenditure on care at the private hospital / private lab or imaging centre?
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Protocol to document cases of

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CASE STUDY REGARDING DENIAL OF HEALTH CARE FROM CHEGUNTA MANDAL, MEDAK DISTRICT, ANDHRA PRADESH

Respondent

Mrs. Nagalakshmi, Karimnaggar Village

Date of Interview

8th August 2003

Investigator

Dr. Abraham,

Community Health Fellow, Community Health Cell,

367, Jakkasandra 1st Main, 1st Block, Koramangala,

Bangalore. - 560 034.

(currently on a field placement with Sanghamitra, working in

Medak District, Andhra Pradesh)

Case Sheet

Mrs. Nagalakshmi, aged 20 years, from Karimnagar village, had her second baby, a girl a fortnight ago. She did not have any complications during her pregnancy or delivery. She and her husband Siddanamulu (25 years old) are daily wage workers who have less than half an acre of land in Karimnagar, a drought prone area 65 kms from Secunderabad. They both had decided that they did not want more children and on the advice of their health worker (Junior Health Assistant – female), Ms. Anuradha of Mutharajpet sub-centre, they opted for the 'operation' at the Chegunta Primary Health Centre (PHC) (i.e., for tubal ligation or tubectomy). She and her husband, their two children and Nagalakshmi's mother and father visited the PHC on 8th August 2003 to seek a tubectomy.

She was informed at the PHC by the doctor Dr. Nayeem that she could not have her tubectomy in the PHC and was referred to a town 'Toopran' (25 kms from Kanyaram) for a tubectomy camp. The PHC medical officer also told her that she suffered high blood pressure and that she should take some Atenolol tablets when she returned home. This prescription was given on a sheet of paper with no prescription date, no dosage, no PHC name or address and no doctor's signature. There was no case sheet prepared. The diagnosis was based without recording the blood pressure and was probably an excuse to justify why she could not get a tubectomy done at the PHC closest to her home on request.

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Some important issues concerning Denial of Health Care

- 1. The respondent and her husband, both illiterate daily wage workers were motivated enough to limit their family size that they come to the PHC seeking a terminal family planning operation.
- 2. They came from their village, Pothanapalli, 14 kms from Chegunta at their own expense, which also meant loss of daily wages for both (also an indication of their high level of motivation).
- 3. They were referred to the PHC by the sub-centre health worker covering their region. This referral was not honoured. This will adversely affect the motivation and credibility of the worker.
- 4. At the PHC they are told that she has high BP without any examination leave alone repeated BP readings, and prescribed a drug without a proper prescription or explanation about usage of medicine.
- 5. Also she was referred to another town for a FP camp without proper or adequate details of date or time of camp, whom to meet or referral slip to an institution in a town which is 25 kms away.

[A case of both denial of 'right to' and 'quality' health care]

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The Right to Health Care is a Basic Human Right!

Towards attaining the Right to health care...

The Government of India has been unable to fulfill it's commitment of 'Health for All by 2000 A.D.' till now. In fact, primary health care services are becoming more and more difficult to obtain for people living especially in urban slums, villages or remote tribal regions. The condition of government hospitals is worsening day by day. Nowadays, in most of the Government hospitals there is inadequate staff, the supply of medicines is insufficient and the infrastructure is also inadequate. There are very inadequate facilities for safe deliveries or abortions in Govt. hospitals. Given the fact that women do not even get adequate treatment for minor illnesses such as anaemia, services for problems such as the health effects of domestic violence remain almost completely unavailable. At the village level, there is no resident health care provider to treat illnesses or implement preventive measures. All hospitals are located in big cities, and here too public hospitals are increasingly starved of funds and facilities. Thus there is lack of availability of government health care services on one hand and the exorbitant cost of private health services on the other. This often leaves common people in rural areas with no other option but to resort to treatment from quack doctors who often practice irrationally. Thus most of the population is being deprived of the basic right to health care, which is essential for healthy living.

The Indian Constitution has granted the 'Right to Life' as a basic human right to every citizen of India under article 21. In article 47 of the Directive Principles of the Indian Constitution, the Government's responsibility concerning public health has also been laid down. Yet the Government is backtracking from fulfilling this responsibility. This is obvious from the fact that the Governments proportion of expenditure on public health services has been declining in successive years.

What can be done in the near future to establish the Right to Health Care?

The year 2003 is the silver jubilee year of the 'Health for all' declaration. On this occasion, Jan Swasthya Abhiyan is launching a nationwide campaign to establish the Right to health care as a basic human right. Some of the following activities are being taken up as part of this campaign—

• We can document case studies of 'denial of health care' in our areas. This process has already started in Maharashtra. Information is being collected in a specific format with the help of a questionnaire. The cases where denial of health services has led to the loss of life, physical damage or severe financial loss of the patient are being emphasised. These case studies would be presented to the National Human Rights Commission. These case studies would help us to depict the real status of provision of the primary health services by the government, would strengthen our demand for improving public health services and would help us in dialoguing with the public health system.

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Jan Swasthya Abhiyan

Let's all join the fight,

For health as a basic right!

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- D. Outbreak of immunisable or other major preventable illness such as measles, cholera, epidemic hepatitis or malaria due to failure of basic preventive or public health measures.
- E. Mental Illnesses Patients who have been denied health care for mental illness in a CHC or higher facility

Some guidelines for activists documenting the case studies.

- At least two case studies should be collected from each district / by each organisation. The attempt should be to document cases where denial of health care has resulted in significant loss to the patient, either in physical or financial terms, to strengthen the case for a human rights violation. Document only those case studies where incidence of denial has taken place in the last 6 months. Collect at least half of the case studies concerning women who have been denied health care. Any case papers / prescriptions or other relevant documents should be collected as supportive documents.
- Take oral consent of the person from whom the information will be elicited. Give that person
 information about the campaign. Tell him / her that the case study may be presented to NHRC, and
 in such case would have relevant implications. Fill the questionnaire only after taking oral consent
 from the person.

Primary Health Center/ Govt. Hospital Services - Survey Questionnaire

Age-	
Sex-	
Address-	С
Date of interview - Name of Respondent (it	different from potient)
Details of care received at	PHC / Hospital

- Location of the PHC / Location and type of Hospital -
- Illness / complaints for which PHC / Hospital was visited -
- Total Number of visits to PHC / Hospital for this illness -
- Date of last visit -

Name of patient-

1. History of last visit in the patients / attendants words -

(Here we want to collect information regarding the main symptoms of the patient, who gave care and what kinds of examination, investigation and treatment were given)

 What were the perceived shortcomings or deficiencies in care? (As perceived by the patient or attendants)

According to patient, was there any adverse outcome because of deficient care? (Death, disability, continued or chronic health problem, severe financial loss e.g. major loan or sale of assets)

2. Medical attention received:

♦ Name of the doctor who attended to you -

If the doctor was not available at that time, then who attended to you -

- 1. Nurse / ANM
- 2. MPW
- 3. Pharmacist
- 4. Any other person, specify
- How long after you reached the PHC / Hospital did the Medical Officer / Doctor attend toyou?
- Was examination / treatment / operation delayed or denied because of non-availability of a nurse, doctor or specialist?

- ◆ In case of an emergency did the doctor immediately attend to the patient? During hospital stay, regarding conditions that required immediate care, was the doctor available to immediately attend to the patient?
- Were nurses or hospital staff available to attend to the patient as and when required?
- Do you think that non-availability of any crucial equipment or supply (oxygen, incubator, anaesthetic equipment, blood, emergency drugs etc.) adversely affected the quality of care?
- Were all the equipments required for the examination and treatment of the patient available in working condition in the hospital?

Diagnosis- (as told by the doctor)

3. Medicines:

- Did you get all the required medicines at the PHC / Hospital?
- Did you have to go to any private medical shop to buy some medicines?
- If so, which medicines you had to buy from private medical shop?
- ♦ How much did it cost?
- Do you have the prescription?

4. Expenditure:

- ♦ Case paper / card made yes/no
- Case paper fee / indoor fees charged
- . Feest charges for other services:

- Did you receive a receipt for the payment made?
- Were you charged excess money at the PHC / Hospital (more than specified rates)?
- If yes, how much excess was charged?
- Did your family have to sell assets (land, cattle, jewelry etc.) or take loans to pay for treatment in the Govt. hospital?

5. Referral:

- Was the patient refused admission or referred to another hospital without giving first aid care?
- If the patient was referred, was ambulance or other vehicle made available for the same?
- ◆ Did the Govt. doctor ask you to avail of any private services (e.g. laboratory services, Sonography / X ray) while you were admitted in the Govt. hospital?
- In case you had to take the patient to a private hospital, which hospital? (name and address of the hospital)
- What was the total expenditure on care at the private hospital / private lab or imaging centre?
- Did your family have to sell any assets (land, cattle, jewelry etc.) or take loans to pay for the private hospital charges?

The Right to Health Care is a Basic Human Right!

Towards attaining the Right to health care...

The Government of India has been unable to fulfill it's commitment of 'Health for All by 2000 A.D.' till now. In fact, primary health care services are becoming more and more difficult to obtain for people living especially in urban slums, villages or remote tribal regions. The condition of government hospitals is worsening day by day. Nowadays, in most of the Government hospitals there is inadequate staff, the supply of medicines is insufficient and the infrastructure is also inadequate. There are very inadequate facilities for safe deliveries or abortions in Govt. hospitals. Given the fact that women do not even get adequate treatment for minor illnesses such as anaemia, services for problems such as the health effects of domestic violence remain almost completely unavailable. At the village level, there is no resident health care provider to treat illnesses or implement preventive measures. All hospitals are located in big cities, and here too public hospitals are increasingly starved of funds and facilities. Thus there is lack of availability of government health care services on one hand and the exorbitant cost of private health services on the other. This often leaves common people in rural areas with no other option but to resort to treatment from quack doctors who often practice irrationally. Thus most of the population is being deprived of the basic right to health care, which is essential for healthy living.

The Indian Constitution has granted the 'Right to Life' as a basic human right to every citizen of India under article 21. In article 47 of the Directive Principles of the Indian Constitution, the Government's responsibility concerning public health has also been laid down. Yet the Government is backtracking from fulfilling this responsibility. This is obvious from the fact that the Governments proportion of expenditure on public health services has been declining in successive years.

What can be done in the near future to establish the Right to Health Care?

The year 2003 is the silver jubilee year of the 'Health for all' declaration. On this occasion, Jan Swasthya Abhiyan is launching a nationwide campaign to establish the Right to health care as a basic human right. Some of the following activities are being taken up as part of this campaign—

• We can document case studies of 'denial of health care' in our areas. This process has already started in Maharashtra. Information is being collected in a specific format with the help of a questionnaire. The cases where denial of health services has led to the loss of life, physical damage or severe financial loss of the patient are being emphasised. These case studies would be presented to the National Human Rights Commission. These case studies would help us to depict the real status of provision of the primary health services by the government, would strengthen our demand for improving public health services and would help us in dialoguing with the public health system.

- On the occasion of completing 25 years of the Alma Ata Declaration, a National Workshop is being organised by JSA on 5th September 2003 in Mumbai, for JSA activists from all over the country. During this workshop, the perspective, issues and campaign strategy regarding Right to Health care would be discussed in detail, and the cases that have been documented would be shared. This would be followed by a National Public Consultation on "Right to Health Care" on 6th September in Mumbai. The Chairman of NHRC, the Chairperson and Secretary of the Health committee of NHRC and the Health Secretary, Central Ministry of Health and Family Welfare are being invited to this programme which will be in the nature of a public hearing. Various public health experts and legal experts will also speak during this program about the Right to Health Care. Selected case studies of denial of right to health care will be presented to the NHRC, and an attempt would be made to build a social consensus on this issue, so that this can be established as a legal right.
- A report on "Status of Health Care in India" is under preparation, which would give an idea about the availability of health care services, differentials in accessibility to these services, state of health care financing and issues related to health care services for specific sections of the population. Well-known public health experts are authoring various chapters of this report. This report could be released in various State capitals, along with case studies and other information related to the state. This could be done during the 'People's Health Assembly anniversary' from 1st to 8th December 2003 (anniversary of the Kolkata and Dhaka Health Assemblies) and would also be an occasion to highlight the situation of health services in each state and the need to establish the Right to Health Care.
- Filing of a Public Interest Litigation (PIL) to establish the constitutional right to health care
 is also under consideration.

These are some of the steps being planned to move towards establishing the Right to health care. Let us join this campaign and strengthen the movement to achieve health care and health for all!

Jan Swasthya Abhiyan

Let's all join the fight,

For health as a basic right!

For further details contact: Dr. Ekbal (National Convenor) - ekbal@vsnl.com

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Protocol to document cases of Denial of Right to Health Care

The purpose of these case studies is to demonstrate how specific persons have been denied basic health care that is expected from Public health services. The idea is to capture events where obvious and major violations have taken place, leading to loss of life, disability, serious health or economic consequences. We should focus on availability of those services, regarding which the public health system cannot deny its responsibility. The idea is to document structural deficiencies and not cases of negligence by individual doctors or staff. However, lack of availability of required medical staff when required, because of significant understaffing should be documented. The objective is not to target individual public health care providers, but rather to document the serious structural deficiencies that exist, which need to be corrected by major strengthening of the public health system.

Some of the major types of cases of this kind are outlined below, however any other similar cases, which come to the attention of activists, can be documented.

Some types of cases of denial of Right to Health Care

(This is not an exhaustive list but rather outlines certain broad categories with examples)

A. General Emergencies: Cases where a patient with a serious medical problem has been taken to a Govt. health centre or hospital (PHC / Rural / Cottage / Sub-divisional / District Hospital) and has been denied the life-saving or stabilising services expected at that facility. The patient may have unnecessarily been referred to a higher facility, leading to delay in treatment and serious adverse consequences, including death. Examples may include non-availability of:

- In a PHC Non-availability of treatment for snakebite or Anti-rabies vaccine; Non-availability of treatment for a child with pneumonia or severe dehydration due to diarrhea resulting in death
- In a Rural hospital: Above or Lack of blood transfusion for a bleeding patient due to accident or bleeding related to pregnancy; Non-availability of emergency drugs leading to serious delay in treatment and death or disability of the patient
- In a Cottage / Sub-divisional / District Hospital: Above or Non availability of emergency surgery leading to death or disability of the patient; non-availability of essential or emergency drugs B. Women's health care: Women should receive certain basic health care related to both reproductive and non-reproductive health problems. Denial may include for example:
- Maternal Health Care: Lack of facility or performance of a normal delivery in a PHC or higher facility; lack of facilities for necessary cesarean operation in Rural hospital or higher facility; unavailability of blood transfusion service to a woman before, during or after delivery; lack of abortion facility leading to septic abortion or other adverse consequences
- Care for burns: A woman reporting with burns in a Rural hospital or higher facility and not receiving care for burns
- C. Major chronic illnesses: Any facility, PHC or above not regularly giving full range of medication to patients with T.B. leading to deterioration of the patients condition including death; Sub-divisional hospital or higher facility not treating/admitting a case of AIDS
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- ◆ Location of the PHC / Location and type of Hospital -
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- ♦ Total Number of visits to PHC / Hospital for this illness -
- ◆ Date of last visit –

Name of patient-

1. History of last visit in the patients / attendants words -

(Here we want to collect information regarding the main symptoms of the patient, who gave care and what kinds of examination, investigation and treatment were given)

•	What were the perceived	shortcomings or	deficienc	ies in e	care? (As	perceived	by the
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2. Medical attention received:

♦ Name of the doctor who attended to you -

If the doctor was not available at that time, then who attended to you -

- 1. Nurse / ANM
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- Do you think that non-availability of any crucial equipment or supply (oxygen, incubator, anaesthetic equipment, blood, emergency drugs etc.) adversely affected the quality of care?
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Diagnosis- (as told by the doctor)

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Main Identity

From: "Jose Utrera" <jose utrera@wemos nl>

To: <sochara@vsnl.com>

Sent: Thursday, December 04, 2003 3:28 PM

Attach: Globalisation and the right to health - presentation Canada&Germany.ppt

Subject: from Wemos case study and presentation Germany

Dear Thelma

Greetings from Holland. It is good to hear from you. I had the intention to write you this week, so I do it now. Did you have a good trip in Germany?

As you asked to Annelies. I am sending you attached a copy of Wemos' presentation in Germany. I wanted to ask you to SEND US AS SOON AS POSSIBLE THE PROPOSAL FOR THE CASE STUDY OF COMMUNITY HEALTH CELL. After receiving it we need to write a contract that Wemos and CHC should sign in order to transfer the financial resources for carrying out the case study. It is so that we need at least to sign the contract before the end of next week, so that the authorization for the payment is approved before the end of the year, otherwise we will lose the money, because the resources for the case studies can not be transferred to next year. The Wemos administration will close by December 18. SO WE NEED TO ARRANGE IT WITHOUT DELAY.

It will be a pity if CHC does not get the resources for carrying out the case study.

I hope you will find the time to write the proposal very soon. As you know, Wemos doesn't need an extensive proposal, only 3-4 pages. I sent you before the guideline for writing the proposal, if you need it again, let me know.

Regards to Ravi and every body there.

All the best!

José Utrera
Project Manager
Health and the Role of the Private Sector
Please reply to jose utrera@wemos.nl
tel +31-20-4352059

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Drop the debt for better health. Support our campaign for debtrelief. See http://www.wemos.ni/campagne

Wemos Foundation, P.O. Box 1693, 1000 BR Amsterdam, The Netherlands tel +31-20-4352050, fax +31-20-4.686.008 http://www.wemos.nl

27

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MOVING TOWARDS A CAMPAIGN ON RIGHT TO HEALTH AND HEALTH CARE - INDIAN CONTEXT

Analysis of cases related to Access to Health Care

Project Assignment Interface of Law, Health and Medicine

> Submitted by Amulya Nidhi ID No. ML&E521/2002 2002- 2004

NATIIONAL LAW SCHOOL OF INDIA UNIVERSITY
BANGALORE
JUNE 2004

ACKNOWLEDGEMENT

My inspiration to work in the area of Right to health has developed while interacting with several groups across the country through Jan Swasthya Abhiiyan. I am grateful to them for channelising my efforts in a proper direction. I would like to deeply acknowledge the contribution of Ms. Shelley Saha, who provided valuable inputs in conceptualizing and for specific response to various drafts. I am also thankful to Dr. Abhay Shukla Dr. Anant Phadke for his time and feedback given for this project.

I would also like to acknowledge the libraries of Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai, Pune, Indore and National Centre of Advocacy Studies, Pune. In addition I would like to thank my colleague Kajal Jain for providing me time so as to complete this project. I recognize the financial and organisational support provided to me by CEHAT for pursuing this course.

TABLE OF CONTENTS

Abbreviations

١.	Health in todays context	5
11.	Right to health and health care - Conceptual framework	8
Ш.	Legal provisions related to Right to health and health care	12
IV.	Denial of Right to health care	16
٧.	Ways ahead - Building a Campaign on the Right to health and health care	20
VI.	Conclusions and Recommendations	24
Ref	ferences	

ABBREVIATIONS

AMS : Adivasi Mukti Sanghthan

CEDAW : Convention on the Elimination of All Forms of Racial Discrimination

CEHAT : Centre For Enquiry into Health and Allied Themes

CPA : Consumer Protection Act

EPI : Expanded programme on immunization

GOBIFFF : Growth, Oral rehydration, Breast feeding, Immunization Female literacy,

Family planning and Food supplements

ICCPR : International Covenant on Civil and Political Rights

ICESCR : International Covenant of Economic, Social and Cultural Right

IMR : Infant Mortality Rate
JSA : Jan Swasthya Abhiyan
MPW : Multi Purpose Worker

NFHS : National Family Health Survey NGO : Non-Governmental Organisations

NHP : National Health Policy

NHRC : National Human Rights Commission

PHC: Primary Health Care

PIL : Public Interest Litigation SPHC : Selected Primary Health Care

UDHR : Universal Declaration of Human Rights

UNICEF: United Nations International Children's Emergency Fund

WHO : World Health Organisation

HEALTH IN TODAY'S CONTEXT

INTERNATIONAL SCENARIO:

In 1978, at Alma Ata the World Health Organisation (WHO) and the UNICEF presented a radical new strategy as a part of the target of achieving 'health for all by the year 2000'. Important principle of the Alma Ata declaration is that health for all can be achieved through primary health care (PHC). It says, "that primary health care is the key to attaining this target. It is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation". The central message of the PHC strategy was a call for equity and social justice.

Such a radical strategy was bound to have its opponents. Within a year of signing the declaration, an alternative approach to PHC, the selected primary health care (SPHC) was being widely disseminated. This approach argued that PHC is not cost-effective, in fact it was too expensive. A more effective method of decreasing mortality and morbidity lay in the selection and prioritisation of selected number of diseases². This approach quickly gained acceptance among donors. UNICEF introduced the growth, oral rehydration, breast feeding, immunization female literacy, family planning amf food supplements (GOBIFFF). The expanded programme on immunization (EPI) was given considerable support by multi-national donors. These selective programmes are, as Rifkin and Walt have argued, a departure from the key principles of PHC³. Its approach is efficiency rather than equity; the market rather than social justice; the disease rather than social, economic and political development. The WHO's Strategy of 'Health for All for the 21st Century is a benign neglect for those who cant afford to be part of the market⁴. For the poor, of both South and North, health for all for the 21st century will not lead to a world where health will be a fundamental human right — a state of complete physical, mental and social well-being and not just the absence of disease and infirmity.

NATIONAL CONTEXT

Health Policy

In the first two Five-year Plans following India's independence there appeared to be a commitment to address the health needs of the populations comprehensively – with preventive, promotive and curative care provided through a wide network of community based health centres, in tune with the recommendations of the Bhore Committee. But in the years that followed, the health sector was driven by technological forces and has become physician centred, reducing the pursuit of health to the provision of medical care, ignoring the broader determinants of health⁵.

Despite significant strides in eradicating communicable diseases and smallpox and in containing malaria and tuberculosis, the health status of vast majority of the people are far from satisfactory. Even though the country had aimed at attaining health for all by year 2000 it has become a distant dream even in the beginning of 21st century. The 1983 National Health Policy (NHP) was meant to arrive at "an integrated, comprehensive approach towards the future development of medical education, research and health services to serve the actual health needs and priorities of the country". Critical of the curative model of

¹ International Conference on Primary Health Care, Airma Ata, USSR, 6-12 September, (1978).

² J.A., Walsh and K.S. warren, "Selective Primary Health Care", 301 (18) New England Journal of Medicine, 967-74 (1979).

³ S.B. Rifkin and G. Walt, "Why Health improves: Defining the issues concerning Primary Health care and Selective Primary Health Care", 23(6) Social Science and Medicine (1988).

WHO "Investigating in Health Research and Development", World Health Organisation (1996).

⁵ S, Saha and TKS Ravindran, "Gender gaps in Research on Heelth Services in India", 4 (2) Journal of Heelth Management, 185-214 (2002).

⁶ Government of India, "Statement on National Health Policy", Ministry of Health and Family Welfare, New Delhi, (1982).

health care, it emphasised a primary health care approach to prevent illness and promote good health. The next decade saw the rural health infrastructure develop with a massive expansion of primary health care facilities. However, this effort was sabotaged by a combination of poor quality facilities, inadequate supplies, ineffective managerial skills, poor planning, monitoring and evaluation. The private health sector has grown phenomenally since, thanks to state subsidies in the form of medical education, soft loans to set up medical practice, etc. accounting for 70-80 percent of all primary care sought, and over 40 percent of all hospital care, in a country where over three-fourths of the population lives below subsistence level. In fact the Draft National Health Policy released by the Ministry of Health and Family Welfare in 2001 further legitimized these trends. It completely omits the very concept of comprehensive and universal health care. The Draft departs from the fundamental concept of the NHP 1983 and the Alma Ata Declaration. The draft, for all the rhetoric on community participation, is replete with "top down" prescriptions. While admitting the wastage involved in running centrally sponsored vertical programmes, it goes on to recommend that we would need to retain many of them!" The draft legitimizes further privatization of the heath sector.

Therefore today we find that the private sector has virtual monopoly of ambulatory curative services in both rural and urban areas and over half of hospital care. The health care market is based on a supply-induced demand and leading to an increase of the cost of health services. Thus India today has a large, unregulated, poor quality, expensive and dominant private health sector, and an inadequately resourced, selectively focused and declining public health sector.

Besides not formulating people's friendly health policy, the State's insufficient commitment to provide health care for its citizens is reflected in the inadequacy of the health infrastructure, low levels of financing and also in declining support to various health care demands of the people. Under structural adjustment since 1991 there has been further compression in government spending in its efforts to bring down the fiscal deficit to the level as desired by the World Bank. This global pressure on the Indian State is evident through its policies of focusing on selective services, for instance RCH and AIDS receive overriding support over primary health care or basic referral services. Another trend that further reduces access is the increased corporate control of health care. New medical technologies have helped complete the commodification of health care.

Given the above context, it is natural that health status of the Indian population would be unsatisfactory. There is no dearth of evidence to show that India's health indicators are one of the worst in the world. India's population is characterised by high levels of morbidity especially among infants and children, women, and the elderly; and high incidence of communicable diseases associated with low levels of sanitation, public hygiene and poor quality of drinking water⁸. Infact the latest Human Development Report shows a downward trend in India's global ranking⁹. For millions of people the enjoyment of the right to health remains a distant goal.

Health Infrastructure

India has a vast health sector, which is broadly divided into the public sector, the private sector and the household. The public sector is comprised of the health care facilities set up by central and the state governments, municipal and local bodies. The private sector consists of private physicians and a range of other practitioners including those practicing non-allopathic systems of medicine, health facilities and corporate hospitals operating for profit and non-governmental organisations (NGOs) operating as non-profit enterprises. Households or self-medication provide first level care in many settings as in many places as health services are unavailable or unaffordable to a large section of the population. Various national level

Response of the National Coordination Committee of the Jan Swasthya Abhiyan to Draft National Health Policy, 2001 (unpublished).

⁸ Abusaleh Shariff, *India Human Development Report,*' New Delhi: Oxford University Press for the National Council for Applied Economic Research (1999).

⁹ UNDP Human Development Report (2000).

studies have shown that people's utilisation of health care is limited by their ability to pay, as well by the availability of services.

In any case today, studies on household expenditure on medical care have shown that poor people trend to seek medical care from the private sector. The irony is that this observation is being seen as a proof of their "willingness to pay" for treatment costs, while this may be more a reflection of an absence of other options than an exercise of "real choice". These observations have legitimized the introduction of "user fees" in public health facilities. We need to understand the move to phase out the state owned services in this context as a logical step towards unregulated primate monopoly in curative medical care.

As argued above, the health sector, today, faces three major challenges: adequate prevention, enhancing equity in access to health care and health status, and getting more value for money. Unfortunately there are no significant initiatives in this regard. There is no visible movement to improve implementation in public sector, or target public sector expenditure to the poor, or restructure private sector to remedy deficiencies of health care market through health insurance and appropriate regulation.

METHODOLOGY

Purpose of the research

Having stated the health scenario of our country and having been involved with various initiatives for 'right to health and health care', I saw this as an opportunity to analyse the concept of 'Right to health and health care' so as to move towards building a campaign for right to health and health care.

Focus of research

The primary questions researched into, the course of the paper is:

- 1. What does right to health and health care mean?
- 2. What are the various legal provisions related to right to health and health care?
- 3. To examine how health care providers in our country are violating these various provisions.
- 4. What are the various initiatives that have taken place towards achieving right to health and health care.

Research methodology

This research is an analysis of secondary materials. Primary data is also used for analysis.

II. RIGHT TO HEALTH AND HEALTH CARE - CONCEPTUAL FRAMEWORK

Human rights are legally guaranteed by human rights law, protecting individuals and groups against actions that interfere with fundamental freedoms and human dignity. They exist to protect individuals from abuses of state power and obligate states to provide the conditions necessary for prosperity and well being. This does not mean that human rights apply exclusively to the relations between the state and the individuals, they, and the principles underlying them, also inform and structure relationship among individuals, particularly where there are power inequalities among those involved (eg between health care provider and patient)¹⁰.

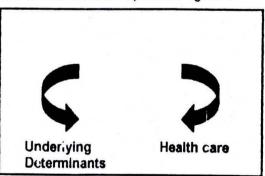
Human rights empower the poor by granting them rights that are legally guaranteed, while at the same time imposing obligations on governments and public bodies such as international organizations. Because human rights are generally legally binding, these bodies are accountable for ensuring that these entitlements cannot be reduced to mere privileges or luxuries or left to the whim of markets.

Every human being has the right to the highest attainable standard of physical and mental health (referred to as "right to health"), conducive to living a life in dignity was first reflected in the WHO constitution (1946) and then reiterated in the 1978 Declaration of Alma Ata and in the World Health Declaration adopted by the World Health Assembly in 1998. According to the General Comment 14 of the International Covenant on Economic, Social and Cultural Rights 'The right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard or health'11. This right is one of the fundamental human rights and is closely related to and dependent upon the realization of other human rights which are the underlying determinants of health, that is access to safe and potable water, adequate food, nutrition, housing, work and education and on provision of health care service.

The Right to health care as a component of the Right to Health

Looking at the issue of health under the equity lens, it becomes obvious that the massive burden of morbidity and mortality suffered by the deprived majority is not just an unfortunate incident. It constitutes the daily denial of a healthy life because of profound structural injustice, within and beyond the health sector. The denial needs to be addressed in a rights-based framework that has gathered momentum in the late 90's, by systematically establishing the right of every citizen to a healthy life. Right to Health is a part of the Right to Life -, the Right to Life with dignity and right to livelihood. Right to health care means having appropriate, accessible and quality health services for all people. According to WHO, to promote the right to health, action is required on two related fronts as depicted in Figure 1.

Fig 1 THE RIGHT TO HEALTH



In May 2000, the Committee on Economic, Social and Cultural Rights, which monitor the International Covenant of Economic, Social and Cultural Right, adopted a General Comment on the right to health.

National Centre for Adviscacy Studies, "Right to Health", 3(5) Advocacy Internet, sept-oct (2001).

¹¹ General Comment 14, CESCR, E/C. 12/2000/4. Twenty second session Geneva, 25April – 12 May (2000).

General Comment applies to nations that have ratified ICESCR and India is one of the states to ratify it. It addresses the content of right to health and the implementation and enforcement of the right to health. According to that the following criteria was set to evaluate the right to health –

- a) Availability adequate number of functioning public health and health care facilities, goods and services.
- Accessibility health facilities should be accessible and affordable to everyone without any discrimination.
- c) Acceptability all health facilities should be appropriate and sensitive.
- d) Quality health facilities must be scientifically and medically appropriate and of good quality¹².

General Comment 14 reaffirms that several "core" obligations have been established in prior human rights instruments: These core obligations, as well as additional obligations are presented in Figure 2¹³.

Figure 2 GENERAL COMMENT 14 OBLIGATIONS REGARDING THE HUMAN RIGHT TO HEALTH

Core Obligations Established in Prior International Human Rights Instruments:

To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups:

To ensure access to the minimum essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone;

To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;

To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;

To ensure equitable distribution of all health facilities, goods and services;

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 all vulnerable or marginalized groups.

Obligations of Comparable Priority:

To ensure reproductive, maternal (pre-natal as well as post-natal) and child health care;

To provide immunization against the major infectious diseases occurring in the community;

To take measures to prevent, treat and control epidemic and endemic diseases;

To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them;

To provide appropriate training for health personnel, including education on health and human rights.

¹² Kinney, E.D. 2001. The International Human Right to Health: What does this mean for our Nation and World?', Indian Law Review, pp 1457-1475.

¹³ General Comment 14, CESCR, E/C. 12/2000/4. Twenty second session Geneva, 25April – 12 May (2000).

A rights-based approach to health entails recognizing the individual characteristics of the population groups concerned. In the 70s and 80s in India there was an initiative to move from health care centred health service delivery to community based health worker programmes, trying to provide affordable and rational care to the villages. The same period also saw the emergence of specific campaigns related to drug policy, hazardous contraceptives, etc. This approach received a set back at the turn of the nineties when resource commitments in the public health sector declined.

This is reflected at one level in slowing down of improvements in health outcomes and the widening rural-urban gap of these outcomes. And at another level the public health care facilities are getting incapacitated because the necessary inputs that are needed to run these facilities are not being adequately provided for. The 2002 National Health Policy unashamedly acknowledges that the public health care system is grossly short of defined requirements, functioning is far from satisfactory, that morbidity and mortality due to easily curable diseases continues to be unacceptably high, and resource allocations generally insufficient (MOHFW¹⁴). The evidence for this is clearly brought out in the changes one sees across the 42nd and 52nd Round National Sample Surveys¹⁵, when over this decade utilisation of private health services, especially in the hospital sector, increased substantially, out-of pocket spending galloped, indebtedness due to health care affected half the users and the proportion of non-utilisation also increased.

Therefore besides having poor health indicators, India also has the dubious distinction of being among the most inequitous countries of the world, as far as health status of the poor compared to the rich is concerned. What is even more serious is the fact that these inequities, instead of decreasing over time, are increasing. Some striking facts in this regard are 16.

- Infant mortality among the economically lowest 20 percent of the population is 109, which is 2.5 times
 the infant mortality rate (IMR) among the top 20 percent population of the country.
- Under-five mortality among the economic bottom 20 percent of the population is 155, which is not only
 unacceptably high but is also 2.8 times the rate of the top 20 percent.
- Child mortality (1-5yrs age) among children from the 'Low standard of living index' group is 3.9 times
 that for those from the 'High standard of living index' group according to recent NFHS data.
- Tribals, who account for only 8% of India's population, bear the burden of 60 percent of malarial deaths
 in the country.

Such gross inequalities are of course morally unacceptable and are a serious social and economic issue, and also exemplify the impact of globalisation-liberalisation policies in widening the gap between the rich and the poor. In addition, such a situation may also be considered a gross violation of the rights of the deprived sections of society, an invisible daily Holocaust. This becomes even more serious when viewed in the context of gross disparities in access to health care ¹⁷-

- The richest quintile of the population, despite overall better health status, is six times more likely to
 access hospitalisation than the poorest quintile of the population. This actually means that the poor are
 unable to afford and access hospitalisation in a large proportion of illness episodes, even when it is
 required
- The richest quintile accounts for 38.5 percent of inpatient days, while the poorest quintile accounts for just 6.6 percent, out of the total hospitalisation days for the population.

^{14.} Government of India, "National Health Policy 2002", Ministry of Health and Family Welfare, New Delhi, (2002).

¹⁵NSS-1987: Morbidity and Utilisation of Medical Services, 42nd Round, Report No. 384, National Sample Survey Organisation, New Delhi; and NSS-1996: Report No. 441, 52nd Round, NSSO, New Delhi; 2000

¹⁶ Abhay Shukla Creating a consensus on the Right to Health Care, Paper presented at National Meeting on Right to Health Care, Mumbai, February 14, (2002).

¹⁷ Abney Shukla Creating a consensus on the Right to Health Care, Paper presented at National Meeting on Right to Health Care, Mumbei, February 14, (2002).

- As high of 82 percent of outpatient care is accessed from the private sector, which is met almost entirely
 by out-of-pocket expenses, which is again often unaffordable for the poor
- About three-fourths of spending on health is made by households and only one-fourth by the
 government. This often pushes the already vulnerable poor into indebtedness, and in over 40 percent of
 hospitalisation episodes, the costs are met by either sale of assets or taking loans.

It is at this context the issue of 'Right to Health and Health Care' is being raised today. The next chapter would highlight how this right can be addressed.

III. LEGAL PROVISIONS RELATED TO RIGHT TO HEALTH AND HEALTH CARE

We can view the justification for this right at three levels – human rights issue, constitutional-legal and socio-economic issue.

Human rights justification

The right to health is solidly embedded in international human rights law. It is explicit in Article 25 of the Universal Declaration of Human Rights (UDHR), adopted by the United Nations (UN) General Assembly in 1948 (WHO). It is not a treaty but a statement of policy and a call to action much like the Declaration of independence. It affirmatively states a human right to health¹⁸:

"Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including...medical care... and the right to security in the event of ... sickness, disability..."

Numerous subsequent international and regional human rights treaties have given further definition to the right to health. In the 1960's the UN sponsored the development of two international covenants that articulate the human rights recognized in the Universal Declaration of Human Rights. These two covenants are the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

The International Covenant on Economic, Social and Cultural Rights (ICESCR)-the so-called Economic Covenant-is the most important in terms of the right to health. Article 12 of ICESCR states that the right to health includes "the enjoyment of the highest attainable standard of physical and mental health¹⁹." The relevant provisions of this covenant are presented in Figure 3.

Figure 3 The International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12

- 1. The States Parties to the present Covenant recognize 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 realization of this right shall include those necessary for:
 - (a) The provision for the reduction of the stillbirth-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.

A human right to health is also recognized in numerous other international human rights authorities that establish prohibitions against government conduct that is detrimental to health. Such treaties include the International Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) of 1979, Convention on the Elimination of All Forms of Racial Discrimination, and the Convention on the Rights of the Child of 1989. Figure 4 presents the health contexts of these conventions:

¹⁸ Universal Declaration of Human Rights, Adopted by the UN General Assembly Resolution 217 A (III) of 10 December 1948.

¹⁹ International Covenant on Economic, Social and Cultural Rights, Adopted by UN General Assembly Resolution 2200 A (XXI) of 16 December (1966). Enforced on 3 January 1976 in accordance with Article 27.

Figure 4

- States shall ensure to (women) access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning..... States shall eliminate discrimination against women in..... health care to ensure, on a basis of equality of men and women, access to health care services....; ensure appropriate services in connection with pregnancy States shall ensure that [women in rural areas] have access to adequate health care facilities, including information counseling, and services in family planning....... (Convention on the Elimination of All Forms of Discrimination Against Women, Articles 10, 12 and 14)
- States undertake to eliminate racial discrimination and to guarantee the right of everyone the right of everyone, without distinction as to race, colour or national or equality before law, the right to public health, medical care, social security and social services...... (Convention on the Elimination of All Forms of Racial Discrimination, Articles 5)
- States recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illnesses and rehabilitation of health (Convention on the Rights of the Child, Articles 24²⁰)

Also of interest, is the 1993 Vienna Declaration and Programme of Action emphasizes the fundamental interrelatedness of political and civil human rights and economic social and cultural human rights. The Vienna Declaration specifically provides:

"All human rights are universal, indivisible and 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 bome 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."

The Vienna Declaration has become a crucial principle in international human rights law recognizing the irreducible truth that all human rights must be recognized if specific human rights are to have concrete meaning²¹.

Reference can be made to other similar international conventions, wherein Government of India has committed itself to provide services related to right to health, for instance the Alma Ata Declaration. National Human Rights Commission (NHRC) has also concerned itself with this issue of right to health.

Constitutional and Legal justification

The issue is, how far these international obligations, agreements, treaties and covenants bind the Indian state and Nationals? Unfortunately, in the Indian Constitution, health is not a fundamental right of citizens, but has to be inferred from the broader parameters of social and economic justice. For instance, the Preamble of the Constitution of India directs the State to initiate measures aiming at improving, the health of the people. The same logic can be stretched to the Fundamental Right – Protection of Life and Personal Liberty.

Only in the Directive Principles is it categorically stated about State's responsibility to health of its citizens and regarding provision of health care. Article 39 states that

²⁰ United Nations Convention on the Rights of the Child, 1989, Adopted by UN General Assembly Resolution 44/25 of 20 November (1989).
²¹ E.D. Kinney. "The International Human Right to Health: What does this mean for our Nation and World?", Indian Law Review, 1457-1475, (2001).

"The state shall, in particular, direct its policy towards securing; that the health and strength of workers, men and women, the tender age of children be not abused and that citizens are not forced by economic necessity to enter a vocation unsuited to their age or strength".

Article 4722 of the Constitution states that

"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......"

Thus, the article 47 of the constitution under the directive principles of state policies define health both in general terms as well as and specifically in terms of health care. Conceptually, this is a great advantage, as the healthy living is not construed only to medical care but also of good nutrition and living standards. This provides a wider scope for legislating on the issue of health and health care.

Though right to health and health care has not been expressly incorporated in the Constitution as a fundamental right, but due to some pioneering and progressive judgments, right to health has acquired that status. Scope for such a kind of interpretation has created by the important judgment of the Supreme Court in the *Paschim Banga Khet Mazdoor Samiti and others V. State of West Bengal and other, 1996*, while interpreting Article 21 the Supreme Court has indisputably held that providing adequate medical facilities for the people is an essential part of the obligations undertaken by the Government in a welfare state. Similarly in the cases *Bandhua Mukti Morcha v. Union of India and others, 1982* concerning bonded labourers, the Supreme Court gave orders interpreting Article 21 as mandating the right to medical facilities for the workers²³. In another landmark judgment in 1995, the Supreme Court stated that right to health and medical aid of workers during services and thereafter, is a fundamental right²⁴. Similar judgments by Supreme Court by interpreting Article 21 has established right to treatment in emergency situation, worker's right to clean environment and health care facilities, right to privacy as a component of health care and also other aspects related to issues of quality of health care services²⁵.

Other Constitutional obligations related to health are that Public health and Sanitation is a state subject as given in the Seventh Schedule, Article 246, list II-6 of the Indian Constitution. This provision assumes importance as this means that without changing any constitutional provisions, the states can make provisions for improving public health. The 73rd and 74th Constitutional Amendments Act, 1992 provide for involvement of Panchayati Raj institutions and Nagar Palikas in all developmental programmes including Public health.

The Consumer Protection Act (CPA) addresses the aspect of medical negligence in the country. But many times CPA acts as a hindrance to provision of emergency medical care as doctors are scared that if the condition of the patient detoriates they may be charged for medical negligence.

The social and economic justification

Health as a basic human right should be viewed holistically and its positive aspect, that is well-being should be acknowledged which would lead to achievement of a socially and economically productive life. The right to equality encompasses within itself the right to a poor patient to get adequate treatment from the state irrespective of the cost.

It is now widely recognised that besides being a basic human right, provision of adequate health care to a population is one of the essential preconditions for sustained and equitable economic growth. The

²² P.M. Bakshi, 'The Constitution of India', Delhi: Universal Law Publishing Co. Pvt Ltd. (2000).

²³ A. Shukla, "The Right to Health Care Moving from Idea to Reality", Paper presented in Media Workshop on Key Issues of Health and Health Care, 21st February, Indian Social Institute, New Delhi, organised by CEHAT (2004).

 ²⁴ Centre for Social Justice "Constitutional Provisions and Supreme Court Judgments on Right to Health", Ahmedabed (unpublished).
 ²⁵ S.V. Joga Rao, "Fundamental Right to Health and Health Care", Country Report on Status of Health care, CEHAT, (unpublished).

proponents of 'economic growth above all' may do well to heed the words of the Nobel Laureate economist Amartya Sen:

'Among the different forms of intervention that can contribute to the provision of social security, the role of health care descrees forceful emphasis ... A well developed system of public health is an essential contribution to the fulfilment of social security objectives.

...we have every reason to pay full attention to the importance of human capabilities also as instruments for economic and social performance. ... Basic education, good health and other human attainments are not only directly valuable ... these capabilities can also help in generating economic success of a more standard kind ... (from India: Economic Development and Social Opportunity by Jean Dreze and Amartya Sen)

This chapter briefly dealt with relevant constitutional provisions and legal enactments regarding health. It is in this enforcement of these obligations that the Courts can play an effective role in safeguarding the rights of the citizens. Supreme Court has upheld right to health through some progressive judgments but it should not be left to the interpretation of judges only. The following chapter would highlight how right to health and health care has been systematically denied to people.

IV. DENIAL OF RIGHT TO HEALTH CARE

In this chapter I would present selected cases where people's right to health care has been violated. These cases are from Barwani and Jhabua districts of Madhya Pradesh and Thane District of Maharashtra, which were presented in a Public hearing in Sendhwa on 4th september 2003 organised by Adivasi mukti Sanghatan and Mokhada on 9th January 2004 organised by Shoshit Jan Andolan. In the public hearing relatives or the patients themselves narrated their suffering of denial of primary health care in public health care facilities. These public hearing were organised as part of Right to health care campaign initiated by Jan Swasthya Abhiyan. These cases were collected by volunteer/staff of CEHAT, activists of Adivasi Mukti Sanghatana, Khedut Mazdoor Chetna Sanghatana/Narmada Bachao Andolan and activists associated with Shoshit Jan Andolan.

Case Study 1

Mr. N, a poor adivasi, was residing with his family of 6 members in J village of a block of Barwani district. In the night of 23^{rd} June, 2003 his son K had a severe problem of vomiting and loose motions. Next day the Multi Purpose Worker (MPW) gave him an ORS packet. When no improvement was observed in the child's condition, it was suggested that he be taken to the nearest Primary Health Centre (PHC), where the medical officer treated him. But, after sometime bleeding started from inside the mouth and nose of the child. At another doctor's suggestion, Mr. N had to shift his child to Sendhwa PHC. Due to lack of money he had to bring the critically sick child in a brick loaded truck. The earlier PHC didn't have ambulance for this emergency situation.

In Sendhwa PHC too, he had to purchase injections and syringes worth over hundred rupees. Later when the condition became more serious, it was suggested that he take the child to Barwani district hospital. But Mr. N, a poor adivasi, did not have money for the transport and further treatment, and ultimately decided to come back to home. On the way back home his child died.

This case study demonstrates how a PHC is not able to provide essential health services, not even an ambulance in an emergency condition, to save the life of an ill child. This case shows violation of Right to a set of basic health services which is guaranteed to us by Article 21 of the Indian Constitution and also Article 24 of the Convention on the Rights of the Child.

Case Study 2:

Mr. D is a 90 year old man of K village of a block in Barwani district. Sometime ago he was not being able to pass urine and was suffering from acute urinary retention. Due to this problem he was taken to Sendhwa PHC for treatment, where the doctor checked him and referred the patient to Karuna Hospital (Private) by saying that he is not able to give him treatment here. Urinary retention is an acute surgical emergency and is simply treated by catherisation, which means a tube has to be inserted to drain the urine from the urinary bladder. This simple facility should be available at the PHC level.

In this emergency condition, the family had to take the patient to Karuna Hospital where the doctor was surprised that catherisation which is easy treatment, could not be given to this old man in the PHC. Hence the person had to suffer and had to spend Rs. 1200/- on treatment, which could have been freely available.

This case shows violation of Right to emergency medical care, and right to essential drugs at an affordable cost. This case shows that these violations amount to violation of Article 21 of the Indian Constitution,

²⁶ The process of Jan Sunwai is presented in the next chapter.

Article 12 of the International Covenant on Economic, Social and Cultural Rights and also Article 25 of the Universal Declaration of Human Rights.

Case study 3

The only family planning service that is mostly provided in the PHC is tubectomy. It is generally conducted in overcrowded camps held occasionally by the government at the PHCs. The main aim of doctors and ANMs in these camps is to fulfill the set target and therefore the operations are often done insensitively and in unhygienic conditions. No attempt is made to explain to the women what is being done to them. Often women from the interior villages are forced to walk long distances to get home the same day.

In one of these type of camps, Ms. M, a 30 year old women from K village, went to the family planning camp held at Sondhwa PHC in Sondhwa block. After her operation, which was conducted in overcrowded conditions, she returned home the same day. A week later she went to the PHC to get the stitches removed and returned home the same day. Two days later she developed severe abdominal pain and was admitted to the civil hospital in Alirajpur. Here she was diagnosed with tetanus and was also told that treatment will not be possible in that hospital and she would have to be taken elsewhere. Since the family did not have the money for further expenses they took her back home where she died three days later.

Here is a case of negligence by the government health facility and reflects the over-keenness of its personnel to fulfill their agenda and targets rather than provide quality health services. Also there is extreme insensitivity as when she was detected to have suffered from tetanus they simply referred her abdicating themselves of all moral responsibility of heath care provider.

This case shows the violation of Right to monitoring and accountability mechanisms and the Right to privacy and the provisions that was specially provided to women under various articles of CEDAW.

Case Study 4

Mr. N, age 65 years, resident of taluka Mokhada had diarrohea. On June 7, 2003 after four to five bouts of loose motions he got dizzy, broke into a cold sweat and became semi-conscious. His wife and some other villagers carried him to the Khodala PHC and the wife went to look out for the lady doctor. It was about 5.00 p.m. The wife met the doctor and told her about her husband's condition. The doctor got very irritated and told the woman that her duty hours were over and she was about to go home. She then asked her to move the patient to Mokhada Rural hospital and left the premises. The woman then went to the residences of the three resident nurses and begged them to treat her husband. They refused saying that they were not on duty and the nurse on night duty would attend to him. The nurse on night duty never turned up so once again she went to the houses of the resident nurses. Finally one nurse Ms. Z took pity and came to the PHC. She gave the patient an injection and administered a bottle of saline. The nurse told them they could not stay in the PHC as there was nobody to attend to them, and she could not stay any longer. Finally the patient was taken to a private doctor, Dr. K in Khodala. He administered another bottle of saline and asked them to go home and return the next day as there was no facility to admit him. The patient spent a total of Rs. 300 for treatment with the private doctor.

A patient with Jiarrhoea, requiring rehydration could not get admission in a PHC. The doctor, supposed to be on call around the clock, refused to attend to the patient and no nurse was available to attend to an admitted patient, forcing the relatives to pay for the expensive services of a private doctor. This case shows the violation of Right to emergency medical care. This case shows that besides violating Article 47 of the Constitution, it also violated provisions of the International Covenant on Economic, Social and Cultural Rights and Universal Declaration of Human Rights, which India is a signatory.

Case Study 5

Mr. M, age 44 years, resident of Taluka Mokhada, fell from a tree on 15th November 2003. He was brought to the Mokhada Rural hospital immediately. The doctor admitted him and asked the relatives of the patient to purchase two bottles of saline, which were administered to him. They then asked them to shift the patient to Nashik Civil Hospital and informed them to hire a private vehicle as no ambulance was available. The next day the patient was taken to Nashik Civil hospital where he was admitted. The doctors there advised the relatives to take him to a private hospital for a C.T. scan as the equipment in the Civil hospital was out of order. The relatives could not afford a C.T. scan so the patient was discharged after fourteen days and has now become crippled due to lack of proper treatment.

A taluka level Rural Hospital there was no ambulance available to transport such a needy patient. The Civil Hospital in a large city like Nashik could not provide the CT scan facility, resulting in a person becoming permanently disabled due to denial of health care. This case shows the violation of Right to a set of basic public health services, Article 12 of the International Covenant on Economic, Social and Cultural Rights, which says that everyone has the right to the enjoyment of highest attainable standard of physical and mental health and also the interpretation of Article 21 of the Constitution as mandating the right to treatment in emergency situation.

Case Study 6

Mr. G, age 2 years, was suffering from diarrohea and vomiting. He was taken to the Tokavda PHC by his mother on the morning of December 25, 2003. The doctor did not examine the child and gave only a packet of ORS. A couple of hours later the mother informed the doctor that the child was running temperature. The doctor did not examine the child but wrote out a prescription for medicine, injection and disposable syringe, all to be purchased from outside. The child was administered the medicines purchased from the private medical store and sent home. The next day the mother returned with the child and she was once again asked to purchase medicines from outside. On the third day the mother did not return with the child as she had no more money to purchase medicines.

Adequate treatment for diarrhoea, one the simplest and commonest illnesses, could not be given by the PHC. This case shows the violation of Right to essential drugs at an affordable cost, which is guaranteed to us by Article 21 of the Indian Constitution and also Article 24 of the Convention on the Rights of the Child.

Case Study 7

Mr. J, age 62 years, resident of Dahanu taluka, was suffering from continuous cough and breathlessness for some time. He approached the Multi Purpose Worker (MPW) of his village working through Kasa PHC for help. The MPW did not give him any assistance so he came to the Cottage Hospital in Dahanu where an X-ray was taken, they examined his blood and sputum and directed him to go to the Kasa PHC to get his treatment for T.B. under the DOTS programme. He was told that the MPW would come to his house and give him his tablets daily, which he was suprosed to consume in the presence of the MPW. After a few visits from the MPW, he went on leave for 15 days and the treatment stopped. The patient went to the MPW's house to ask for the tablets but he refused to give them to him and said that he would personally administer them to him at his house. After repeated requests to the MPW, the patient complained to the doctor about the abrupt stoppage of his treatment. The MPW made only one visit gave him tablets for a few days after which the treatment was stopped till today.

Regular treatment for a case of tuberculosis, the core activity of the National TB Control Programme, was denied despite his taking repeated initiative to obtain treatment and the patient being enrolled under the much-publicised 'DOTS' programme. This case shows the violation of Right to a set of basic public health services. This is a violation of the International Covenant on Economic, Social and Cultural Rights and also the provisions guaranteed by the constitution.

Case Study 8

Ms. U, age 12 years, resident of Jawhar taluka went to school on 27th November 2003 as usual, after an early lunch at about 10.00 a.m. She vomited three times in school and then came home. She continued vomiting a number of times. At about 7.00 p.m. when her parents returned from work they rushed her to the Jawhar Cottage Hospital. She was admitted in the hospital, given one injection and some tablets but her vomiting did not stop. Her father requested the nurse on duty to attend to her but she did not pay any heed instead she scolded the parents, saying that the girl was dirtying the hospital. The parents were asked to give her glucose water orally which they administered the whole night. The girl could not sleep, she had high fever and she was crying incessantly, however no medical staff came to see her despite several requests. At about 6.00 a.m. the next day the girl's stomach become distended. Even then no medical staff on duty attended the patient. At 11.00 a.m. the doctor came on his routine round, examined her pulse and moved on. The parents requested the doctor to give the child intravenous saline, since she was not able to swallow the glucose water but he did not pay any heed. At about 12 noon the child became unconscious. The father rushed to the doctor who was on duty at Jawhar cottage hospital, informed him. The doctor asked him to bring the patient to his chamber. By the time they brought the patient to the chamber, she had expired.

While in the Cottage hospital, the child was in severe distress for more than 12 hours, but was not given adequate attention required to diagnose or treat the underlying problem. The child died, and adequate medical attention not being given in time was a likely contributory cause. This case shows the violation of Right to a set of basic public health services. This is a violation of the International Covenant on Economic, Social and Cultural Rights, the Right to life, guaranteed by the constitution and the right of the child recongnised by the Convention on the Rights of the Child.

The above cases show that the existing situation is very dismal and the changing political economy does not show too much promise of change for the betterment of health, unless of course there is a radical transformation in the political commitment. For this to happen the support of civil society pressures and demands for a transformation of the healthcare and rehabilitation dispensation will be needed. We need to move towards the objective of establishing health care a Fundamental Right in the Indian Constitution. This would be a prolonged and challenging process, and would involve political mobilization and widespread public awareness besides other things. The time has come to begin asking as to how the human rights related commitments and concerns will be translated into action in a realistic, time bound and accountable framework. The following chapter would present the efforts undertaken so far in this direction.

V. WAYS AHEAD- BUILDING A CAMPAIGN ON THE RIGHT TO HEALTH AND HEALTH CARE

Right to health and healthcare is a fundamental social and economic right recognised by the International Covenant. But such a demand is not on the political agenda in India. This massive health care deprivation amidst potentially adequate health care resources needs to be addressed by establishing the right to every citizen to basic health care, accompanied by operationalising a system, which would ensure universal access to health care. The first step towards this direction was taken in the International Conference on Primary Health Care, meeting in Alma Ata in 1978. The Conference reaffirmed that health is a fundamental human right and that the attainment of the highest possible level of health is a most important worldwide social goal²⁷. It says that governments have a responsibility for the health of their people, which can be fulfilled only by the provision of adequate social measures.

For building an effective campaign for right to health the central task must necessarily be the task of mobilizing those who are personally facing the brunt of the anti-people policies. Any movement that is not based on the mobilization of this section is seriously limited. Though the slogan is 'People's health in People's hand', it is yet to be placed in people's hand because most organisations and networks currently focusing on right to health come from middle class backgrounds. Though even with this limitation certain demands like increase in budgetary allocation and expansion of public health services form a ground for action – but they are not adequate to form a movement.

For mobilizing this section, two approaches are useful. One is the articulation of comprehensive radical critiques, if possible with alternatives, for making out the correct political position. Another approach is to engage in lobbying and advocacy for policy changes and shaping of a public opinion. One way to generate a public debate is to take the formal judicial route, filing of Public Interest Litigation (PIL), which would draw media attention and would put pressure on the political sphere. This could lead to short term gains and this can help in sustaining mass action. But to build a larger public campaign for the 'right to health and health care' – a nation wide initiative Jan Swasthya Abhiyan (People's Health Movement – India) was initiated. Jan Swasthya Abhiyan is a campaign platform that has emerged from the People's Health Assembly process in India in 2000. It forms the Indian regional circle of the global People's Health Movement, and is a coalition of 20 National networks and several hundred organisations from all over the country working in the area of health, people's science, women's issues and development.

Jan Swasthya Abhiyan (JSA) in India has voiced a demand to make health care a right, but this requires a widespread awareness campaign and participation of many more civil society groups. This chapter would describe the various initiatives that are undertaken in the country by JSA in the direction of making health care a right.

In India to achieve right to health and health care two parallel process is needed, firstly by demanding from the Government, amendments in law and secondly by building pressure from people. As at present asking right from the formal judiciary is a long way process and it is expensive for a common man to fight with the system individually, therefore a parallel Judicial System was initiated, which is accessible and affordable to a layperson. It was known as people court. In ancient time also in villages there was a system of panch system, which solved day-to-day crime and conflicts in villages. Still in some parts of Rural India this system is functioning.

²⁷ International Conference on Primary Health Care, Alma Ata, USSR, 6-12 September, (1978).

Public hearing as a means for creating public discourse and people's mobilization-

In India, Jun sunwai as an innovative advocacy strategy was initiated by Mazdoor Kisan Shakti Sanghatana (MKSS), Rajasthan. It was initiated as part of Right to information campaign. After this in several parts of country Public hearing was organised on different social issues.

Jan Swasthya Abhiyan has emerged as a premier national level platform in India with a clear Rights-based approach to health. State and national level activities have included facilitation of 'People's Health Enquiries' in over 200 districts all over the country. In continuation with its pursuance of health rights, JSA organised Public hearings (Jan Sunwai) in various parts of the country. Here I am going to present the process of conducting Public Hearings.

Meaning of Jan Sunwai-

"Jan Sunwai is a process in which any issues related to social sector is addressed to a panel of experts from related field". In past few years Jan Sunwai (Public hearing)- as a model has become very popular in which experts from related field act as a judge and activist as a lawyer and government representative as a third party. In public hearing public officials and representative are invited to defend themselves in these hearings. This strategy encourages people to speak out fearlessly and give evidence against the misdeeds of the administration. Like in court, common people are allowed to listen to the judgments, in the same way the Public hearings is not limited only to the people actually suffered, but lawyers, intellectuals, academicians, and journalists can also be a part of the process. The judge or panel gives recommendations after listening to people's voices for immediate action so as to make relevant changes in the policy. In public hearing villagers/ common people are informed in advance about place, date and others details to be discussed. A large number of people from all walks of life participate in the hearings.

The strength of public hearing is it is being organised in local language. This encourages the poor, who are otherwise unheard of to express their negative encounters with the government system. Public hearing was not only effective as an advocacy strategy, but as a means to give the poor an opportunity to voice their dissent. It helped to increased the strength and bargaining power of people in relation to state machinery.

The well planned public hearing not only serve as a means to create mass mobilization and grassroots mobilization, but also created a lot of news value in the media. So public hearing had multiple strategic functions. Here I would present few instances of Jan Sunwai held in the country in the last one year on the issue of health care.

Regional level - Jan Sunwai - Sendhwa, Madhya Pradesh

Jan Swasthya samiti, Sendhwa, Madhya pradesh had organised a public hearing, which was hosted by Adivasi mukti Sanghatana, Sendhwa on the issue of peoples right to health on 4th September 2003. The idea of organising a Jan Sunwai was initiated in a meeting of Adivasi Mukti Sangathana at Niwali in July 2003. The process details of this important step forward in the health movement in Western Madhya Pradesh (MP) are as follows.

Organisational groundwork: In this process at first village meetings were held and specific cases of denial of health services, which led to either loss of life or endangered life were documented. Activists of POs, Volunteer, MSW fieldwork students and staff associated with CEHAT and Ashagram, documented these cases. Simultaneously a meeting was organised in the month of August in Sendhwa by the Jan Swasthya Samiti, Sendhwa to discuss the present situation of public health services after 25 years of Alma Ata Declaration. In that meeting it was felt that these findings should be discussed with the people to make a wider impact.

Documenting situation of staff, services and infrastructure in PHCs, CHCs and District hospitals: In order to strengthen the advocacy to right to health care campaign, a survey was conducted in Badwani and Jhabua district by Jan Swasthya Samiti to document the situation of public health services in these areas. Here based on the checklist information was collected through observation and discussion with PHC/CHC staff. Information was collected from a total of 31 PHCs, 5 CHCs and 1 District hospital. Secondary data available at District Health Departments were collected to supplement the field level data. Based on this information a report was prepared which highlights the stated and actual provision of public health services in the districts.

Mobilization of People: In this process, activists of Adivasi Mukti Sanghthan (AMS) did mobilisation at village level. Besides other NGO/Peoples Organisation like Khedut Mazdoor Chetna Sangath/Narmada Bachao andolan also mobilised people from Jhabua district to participate in Jan Sunwai. Almost all active groups at the area participated in this process. Keeping in view to address this issue to middle class people, doctors, media, press, teachers, lectures were also invited and were convinced by JSS people to participate in the public hearing.

The event - Jan Sunwai: This entire process culminated in the Jan Sunwai organised on 4th September 2003 at Sendhwa in which around 200 people participated. It was organised by Jan Swasthya Samiti, Sendhwa and hosted by Adivasi Mukti Sangathana, Sendhwa. A panel consisting of Dr. Anant Phadke, health activist from Pune, Dr. T.Sundararaman, Health Advisor to Chattisgarh government, Dr. Rahul Sharma, Convenor of BGVS, Gwalior were present for the Jan Sunwai. The District Administration and Health dept were also invited for this public hearing, but they did not come for the hearing. Representatives of 9 blocks from Barwani and Jhabua districts presented their situation of public health system failure of the area. The people who faced denial of health care presented several cases. The panel was shocked to find that appropriate treatment is not given even in simple cases of diarrhoea and no treatment is available in some areas for snakebite and dog-bite. Their report says "Such gross deficiencies are a matter of shame when we enter the 21st Century". Based on that the panel suggested some recommendations and expressed their comment / opinion about the issue. They recommended, "The CMHO needs to seriously take note of these gross deficiencies and take up remedial measures". As follow-up this report, the recommendations of the panel were submitted to District Administration & Health Department.

Subsequently it has now been decided by Jan Swasthya Abhiyan, MP that such type of Jan Sunwais would be held in different areas of the state. Like Madhya Pradesh in other states also public hearing were organised as part of Jan Swasthya Abhiyan.

National Consultation on Health Care as Human right

As a part of the campaign, on the 5th -6th sep 03, a national workshop and national public hearing of the denial of health care were held in Mumbai, the latter in the presence of the chairperson of the National Human Rights Commission (NHRC). It was attended by over 250 delegates from 16 states, dedicated to a broad spectrum of health and right based movements, including rights for women, children, people affected by HIV, displaced people, people in areas of conflicts, workers in the unorganized sector, as well as number of academicians, policy analyst and other interested citizens.

The workshop included a series of presentation, which provided the background to the issue of health care as a right, and looked at key elements of health care for groups most vulnerable to the violation of health care as a human right.

In the Consultation, Justice Anand, Chairperson of NHRC mentioned in his inaugural speech that the Supreme Court has taken a view that health care is a fundamental right. At the end of his speech he stated

his clear position that "Obligation of the state to take care of primary health is paramount, total and absolute. The state cannot avoid its constitutional obligation on account of financial constraints"28

Other Strategies:

Besides building a public opinion through the above strategy, the other approach adopted is *initiating a dialogue with a wide variety of professional associations* like Indian Medical Associations, Medical Council of India, universities and academic research institutions and networks. This is necessary to build up an ethos of support to the campaign and would also help to counter the potential opposition of the medical industry or those who see a threat in this campaign.

The other step that is adopted is to try and evolve and integrate other health care systems and traditions would greatly enhance the demand and support base.

Jan Swasthya Abhiyan also organised a 'Public Dialogue with political parties on Health Issues' on 12th March 2004 in Delhi before the General Elections 2004. Around 300 JSA associated persons attended this public dialogue. This event involved representatives from different political parties, representatives from the media both print and electronic, expert panelists and speakers, and JSA related health activists from a dozen states. Members of some political parties also promised that they would take up issues related to health in their campaign and also in the assembly.

Besides these above mentioned national level initiatives, various state units of the JSA are also involved in state level campaigns to make right to health a reality.

The concluding chapter would focus on the issues that needs to be addressed further and strategies that need to be adopted to make "Right to Health and Health Care" a reality.

²⁸ Jan Swasthay Abhiyan, "Report of the National Workshop on Right to Health Care and National Consultation on Health Care as Human Right", 5-6th September, organised by CEHAT, (2003).

VI. CONCLUSIONS AND RECOMMENDATIONS

Like all rights, the right to health care could not be realized with judicial intervention alone, but require tremendous action by civil society. The law was only a part of the social framework with which the right to health care could be realized. The other integral part is civil society, which now needs to be strengthened through education, and a consciousness of the value of human life. The last few years has aiready demonstrated the tremendous power of the civil society in trying to achieve health care rights. The right to healthcare campaign is trying to bring into light the readiness at the community members to contribute towards demanding health care as their fundamental rights. This needs to be strengthened further.

After independence the state gave emphasis on enactment of new laws, modification of the colonial law and the judiciary developed case laws to consolidate people's entitlement of health care and to an extent, the rights. This development took place on the basis of numerous recommendations made by various committees like the Bhore Committee(1946) and Mudaliar committee(1961). The Bhore Committee recommended formulation of a **Public Health Act**, which was subsequently tried by Mudaliar committee to formulate such an act. The Mudaliar committee drafted a Model Public Health Act, which was a very comprehensive document²⁹. This draft Act aimed at being the legislative counterpart to implement fully the recommendations made by the Bhore Committee and Environmental Hygiene Committee reports and has envisaged a comprehensive and integrated health service covering all the essential fields. The Act therefore laid down statutory obligations on the State to ensure the fulfillment of the objective³⁰. The subsequent committees failed to take their recommendations to logical conclusions. Recently the Bajaj Committee(1996) after relooking at the act has also recommended uniform adoption of Public health act. This needs to be implemented soon.

The initiative to bring healthcare on the political agenda will have to be a multi-pronged one and fought on different levels. The idea here is not to develop a plan of action but to indicate the various steps and involvements which will be needed to build a consensus and struggle for right to healthcare. To establish right to health and healthcare with the above scenario certain essential steps will be necessary, which are listed below:

- Implementation of different provision already given though different international treaty. Pressurizing
 international bodies like WHO, Committee of ESCR, UNCHR, as well as national bodies like NHRC.
 NCW to do Effective monitoring of India's state obligations and demand accountability.
- Lobbying with parliamentarians to demand justifiability of directive principles. The directive principles
 gives full scope to the parliament to make right to health care a fundamental right. Filing public
 interest litigation (PIL) on right to healthcare to create a basis for constitutional amendment.
- Besides, in the absence of a will to make it a fundamental right, there is also scope for enacting a
 simple but comprehensive legislation for making right to health care an effective practical reality.
 Implementation of Model Public Health Act (if necessary with some modifications) in all states³¹. If
 the public health system fails to deliver basic health services, it should be treated as a legal offence,
 remedy for which can be sought in the courts of law.
- To establish a district and State level systems for People's monitoring and accountability mechanism to oversee the implementation of the various provisions.
- · Generating a political commitment through consensus building on right to health care in civil society.
- Development of a strategy for pooling all financial resources deployed in the health sector

²⁹ Amar Jesani, "Right to Health Care: Entitlement and Law", Laws and Health Care Providers, CEHAT, Mumbai (1996).

³⁰ Mudaliar Committee, "Appendix B – 38, Salient features of the Draft Model Public Health Act", Report of the health Survey and Planning Committee, Vol 2, Government of India, Ministry of Health and Family Welfare, (1961).
³¹ This Act after modification was simulated by the committee of the health Survey and Planning Committee.

³¹ This Act after modification was circulated to all states for its implementation in 1987. It was to be examined by all State health authorities and local health authorities to suit local and national needs.

- The medical councils must be made accountable to assure that only licensed doctors are practicing
 what they are trained for. Further continuing medical education must be implemented strictly by the
 various medical councils and licenses should not be renewed (as per existing law) if the required
 hours and certification is not accomplished.
- Strictly regulate the private health sector as per existing laws, but also an effort to make changes in
 these laws to make them more effective. This will contribute towards improvement of quality of care
 in the private sector as well as create some accountability.

The agenda for health reform is long, far-reaching and tortuous, arguing for rethink on the role of public health sector and for restructuring of the private sector. To conclude, it is evident that the neglect of the public health system is an issue larger than government policy making. The latter is the function of the overall political economy. Under capitalism only a well-developed welfare state can meet the basic needs of its population. Given the backwardness of India the demand of public resources for the productive sectors of the economy (which directly benefit capital accumulation) is more urgent (from the business perspective) than the social sectors, hence the latter get only a residual attention by the state. The policy route to comprehensive and universal healthcare has failed miserably. It is now time to change gears towards a rights-based approach. The opportunity exists in the form of constitutional provisions and discourse, international laws to which India is a party, and the potential of mobilizing civil society and creating a sociopolitical consensus on right to health care. There are a lot of small efforts towards this end all over the country. Synergies have to be created for these efforts to multiply so that people of India can enjoy right to health and healthcare. While the course and outcome of these efforts would depend on the much larger political situation, the following slogan should continue till we achieve our goal of a more humane society.

Health for All - Now!

The Right to Health is a basic human right!

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2, Rengaraman Complex. Madurai Main Road. **KAYATHAR - 628 952** Tuticorin Dist. Tamil Nadu. S. India.

5350/A/5 Ref:

Peoples Health Movement Secretariet C/o Community Health Cell,#367-srinivasa Nilaya, Jakkasandra I main, I block, Koramangala, Bangalore, India-560034

Dear sir/Madam,

"Greetings from our AWARD"

AWARD is a Non-Governmental Voluntary Organisation based on Tuticorin District of Tamilnadu Since last 12 years. We co-ordinating one NGOs Net work team in the name of "Southern Collective for Strategic Development" [SCSD] This body is registerd one. The spread of HIV/AIDS all over India poses a grave challenge in the areas of health, social and econamic development. The AWARD project was created to tackle this menace in South Tamilnadu.

GOAL:

To reduce the sexual transmission of HIV/AIDS in Tamilnadu, as it is the majour mode of transmission accounting for 90% of HIV infections.

STRATEGIES: AWARD has four fold strategy to achieve its goals.

- . 1.Small NGO support and technical assistance[network based]
- 2.STD prevention and control
- 3. Condom promotion,
- 4. Behaviour Change Communication

STD PREVENTION AND CONTROL:

Sexually Transmitted Disease(STD) increases the risk of contracting HIV/AIDS. Therefore prevention of STD is crucial.

CONDOM PROMOTION:

Condoms are very effective in preventing the spread of HIV/AIDS through sexual means. And creating more condom outlets(traditional and non-traditional)in the targer areas.

BEHAVIOUR CHANGE COMMUNICATION:

To bring about a change in the people towards safer behaviour, AWARD chalked out the following strategies.

- *Community levl intervention to create a well informed environment.
- *Individual level communication to bring about behaviour change.
- *Technical assistance to improve communication skills of small NGOs.
- *Trained NGO staff to recruit peer educators to reach the target audience.

AWARD marked off priority areas to conduct its activities, where the chances of reaching the high risk group are more. The priority areas are our working south Tamilnadu for following

- *Highly Populated places,
- *Industrial areas,
- *Highways
- *Tourist Centres,

lib - MM) Ands file

Regd, Offfice: 35 Pudukottai, Panneerkulam (PO) Via: Kayathar, Tuticorin Dist., pin -628 952

*Places of worship

As a result of AWARD sustained HIV/AIDS prevention activities in these places, studies reveal that there is a marked difference in the behaviour of the people, such as

*a sharp decline in the non-regular sexual partners among truckers.

*a rapid increase in condom usage among women in prostitution and truckers.

OPERATING AREAS:

AWARD is a mothor NGO of SCSD network of 16 small Ngos in south Tamilnadu. We covering Five districts like Tuticorin, Tirunelveli, Kanyakumari, Virudhunagar, and Sivagangai districts. Each district we selected for 3 genuine organisations only. We clear about no any duplication areas of operating by Tamilnadu state Aids control society, and APAC funding project areas. Only we covering out of covering important new target places.

CORE PRINCIPLES AND VALUES:

- *The value of peer education and community participation in disseminating crucial information about HIV/AIDS prevention.
- *The commitment to constant innovation and learning in response to challenges.
- *The principle of confidentiality in protecting records and information pertaining to target population.
- *The commitment to professionals standards in all areas of work.
- *The development of synergy between AWARD, affiliated small NGOs , community members, government agencies, and departments,
- *The commitment to capacity building and sustainability of technical strategies and community networks.
- *The development of consistent messages and support structures to aid populations in implementing behaviour change.

PROJECT PERIOD:

We want support minimum three years, maximum five years.

BY END OF THE PROJECT AWARD HOPES TO HAVE ACHIVED THE FOLLOWING:

- *A network of small NGOs involved in AIDS prevention
- *Programms to build the capacity of NGOs to ensure quality intervention projects
- *Increased number of people aware of STD/HIV/AIDS preventive measures.
- *Promotion of Condom sales and use.
- *Identifying more PLWHA in these areas.

REQUEST:

Our south districts of Tamilnadu more affected peoples in HIV/AIDS. Now our state HIV/AIDs patients are 52036(june-2005,NACO statistics) More childres are affected daily for semi and full orphan. But not reach the awareness to village poors, Agriculture labourers, street vendors, industrial workers, hotel workers, mehanic workers and somany groups. So, we want to your kind humanitarian support of HIV/AIDS awarenss in our South Tamilnadu. Our India HIV/AIDS patients 1,10,856 (NACO-june2005). so, Tamilnadu is a first state of India in HIV/AIDS affecting. This is very dangerous one. So, its emergency of to complete aware of all sectors of the peoples. So, we kindly requested to you please support of your funding for fight against HIV/AIDS in Tamilnadu. We kindly requested to you please send your Application form, Guidelines for project proposal, model budget breakdown and other informative materials send as early as possible.

Thanking You,

IS.KARUPPASAMYI

Yours Sincerely.

DIRECTOR-AWARD CHAIRMAN-SCSD[NETWORK]

Director,

AWARD L'FUST KAYATHAR-628952. Tuticorin District.

Ph; 04632 - 261603

INFOCAP INFORMATION SHEET

Past, Ongoing, and Planned Projects

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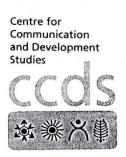
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8th October, 2005

Dear Reader,

We are happy to bring you the third issue of InfoChange Agenda.

InfoChange Agenda has been conceived as a quarterly dossier that informs civil society on crucial issues of sustainable development and social justice. It is designed to enable concerned citizens in India /South Asia to marshal salient information, facts, figures, perspectives and reportage on issues that are, increasingly, being pushed into the margins of mainstream media and public debate.

Agenda is put together every quarter by InfoChangeIndia's extensive network of journalists, development analysts and activists. This network has collaborated over the last few years to build InfoChange News & Features (www.infochangeindia.org), one of India's most-visited online resource bases on development and rights issues.

The first issue of Agenda was on industrial pollution and hazards, 20 years after the Bhopal gas tragedy. The second issue was on access to public healthcare in India, with reports on the spiraling costs of public healthcare and shrinking government spending on healthcare.

The third issue of Agenda focuses on the 'Politics of Water'. The articles deal with control of water resources, the worth of water today, and raise questions about those who suffer and gain as a result of water scarcity.

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We also welcome your feedback on the contents of this issue, and your ideas and contributions for forthcoming issues of Agenda.

With best wishes

For Hutokshi Doctor & John Samuel

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Main Identity

From:

"Romeo Quijano" <romyquij@yahoo.com>

To:

<pha-exchange@lists.kabissa.org>

Sent:

Thursday, October 27, 2005 12:48 PM

Attach:

INFOCAP INFORMATION SHEET - withexplanations.doc

Subject:

PHA-Exchange> Invitation to participate in INFOCAP

October 27, 2005

Dear Colleague,

Greetings!

We are writing to invite your organization to participate in the Information Exchange Network on Capacity Building for the Sound Management of Chemicals (INFOCAP), an information exchange mechanism to enhance effective coordination and cooperation among countries and organizations involved in activities related to sound management of chemicals.

The INFOCAP project will strengthen the level of NGO intervention in global and regional chemical safety activities which have become especially important in influencing emerging chemical safety policies and regimes in various parts of the world, particularly in developing countries. We are confident that through a transparent and cooperative mechanism of information exchange, we can contribute significantly, and become beneficiaries as well, in improving and expanding institutional capacities for the sound management of chemicals in order to protect health and the environment.

Health Alliance Against Toxics(HEAL Toxics)/Pesticide Action Network(PAN) Philippines (Ms. Sampaguita Quijano as Coordinator) has been designated to coordinate the participation of Public Interest NGOs in the INFOCAP. We will help in gathering and promoting appropriate information and materials pertaining to activities related to chemical safety issues and in identifying specific areas of need that may potentially find support through INFOCAP facilitation. As such, we shall provide an interface to public interest NGOs' contributions and access to the INFOCAP services.

In line with this, we would like your organization to please fill up the attached INFOCAP Information Sheet and send the accomplished form to us via email. You Printout

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COMMUNITY HEALTH CELL

Society for Community Health Awareness, Research and Action No. 367, Srinivasa Nilaya, Jakkasandra I Main, Koramangala, Bangalore - 560 034.

Month: DECEMBER, 2003

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may choose any of your past, ongoing, or future projects (e.g., environmental toxins and pollutants, pesticide monitoring, chemicals poisoning, etc.) to put in the information sheet. Once we receive the form from you, we shall send it to the INFOCAP website (www.infocap.info), where the information about your project and your organization may be viewed by potential funding organizations and other NGOs. Alternatively, you may send us information about any of your projects and we can fill up the information sheet for you.

In turn, your organization may use INFOCAP as a web-based tool to find out more about ongoing projects in other organizations, get information about potential funding agencies, and obtain training and guidance documents that you may want to use. Please visit www.infocap.info, or email us for more information. Thank you very much!

Sincerely yours,

Dr. Romeo F. Quijano (Sgd.)

> > Ravi Narayan > Coordinator > PHM Secretariat (Global) > c/o CHC > No. 359 (old No. 367)

> Srinivasa Nilaya, Jakkasandra 1st Main

> 1st Block, Koramangala > Bangalore - 560 034. India > Tel: 00-91-80-51280009 > Fax: 00-91-80-25525372

> Email: secretariat@phmovement.org > Website: www.phmovement.org

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"Bom-VibhutiP" < lara1984@bom5.vsnl.net.in>, "Bom-AnilP" < anilpil@vsnl.com>,
"Bom-PadmaP" < nprakash@bom3.vsnl.net.in> "Pom PaviD" < ravidusesl@vsnl.com>,

"Bom-PadmaP" <nprakash@bom3.vsnl.net.in>, "Bom-RaviD" <raviduggal@vsnl.com>,

"Nashik-Dhruv-1" <mankad@vsnl.com>, "Pune-Anant (H)" <amol_p@vsnl.com>,

"Pune-CEHAT-MohanDeshpande" <cehatpun@vsnl.com>,

"Pune-Manisha-Masum" < masum@vsnl.com>

Dear Friends,

For last few months there has been lots of discussion within the UN on the question of right to health care. The UN special Repporteur for the Committee on Economic, Social and Cultural Rights has/have prepared a general comment on the right to health care for discussion within the UN. A copy of it is attached herewith. He would like to receive comments from all concerned on the draft. If you have any comment, please send it directly to him, or to me.

With best wishes.

Amar (Amar Jesani)

Dear all,

Please find attached documents, one of which is the draft General Comment on the Right to Health written by the Special Rapporteur Eibe Riedel of the Committee on Economic, Social and Cultural Rights. He would appreciate any comments, if ready prior to the session, [22nd CESCR session from 25 April to 12 May 2000] sent directly to him at the following address

Mr. Eibe Riedel, Member, Committee on Economic, Social and Cultural Rights

University of Mannheim Schloss, Westflügel 68131 Mannheim, Germany

Tel.: (0049) (621) -181-1417/8 (profess.)

Fax: (0049) (621)-181-1419

E-mail: riedel@jura.uni-mannheim.de Tel.: 0049-63-21-848-19 (private)

with a copy to the secretary of the Committee on Economic, Social and Cultural Rights, Mr A.Tikhonov at the following address: "Alexandre Tikhonov" <atikhonov.hchr@unog.ch>

Sorry about the short notice

best wishes

Peter Hall

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4/11/00 9:43 AM

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Name: 2DraftGC.14.doc

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Encoding: 7bit

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Subject: Fw: Draft General Comment on art.12 of the ICESCR
    Date: Sun, 9 Apr 2000 22:59:41 +0530
   From: "Amar Jesani" < lara1984@bom5.vsnl.net.in>
Reply-To: "Amar Jesani" < jesani@vsnl.com>
      To: "Mah-Dolke" <aaasn@nagpur.dot.net.in>,
          "Ahd-Charul/Vinay-1" <abhigamc@wilnetonline.net>,
          "Blore-Aditi" <aditiyer@yahoo.com>, "Blore-CHC" <sochara@blr.vsnl.net.in>,
          "Blore-GitaS-IIM" < gita@iimb.ernet.in>, "Bom-CEHAT-Sumita" < cehat@vsnl.com>,
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          "Nashik-Sham" <ashtekar@giasbm01.vsnl.net.in>,
```

CHC

From:

"Debabar Banerji" <nhpp@bol.net.in>

To:

"Claudio" <claudio@hcmc.netnam.vn>

Cc:

"PHM" <secretariat@phmovement.org>; "pha" <pha-ncc@yahoogroups.com>

Sent:

Saturday, October 02, 2004 11:36 AM

Subject:

[pha-ncc] Re: PHA-Exchange> Food for reversing a faulty process of thought

Dear Dr Shuftan

Once again, you have raised an important issue. PHM has to take a stand on this. Regards, D Banerii

---- Original Message ----

From: Claudio To: pha-exch

Sent: Saturday, October 02, 2004 7:33 AM

Subject: PHA-Exchange> Food for reversing a faulty process of thought

Human Rights Reader 81

ON NGOs AND THE RIGHTS OF WINNERS AND LOSERS

- 1. NGOs became players on the political and human (or people's) rights stage (HR) long ago --both at the national and the international level. As such players, in the Third World, many of the Northern NGOs have unfortunately too-oftenand-for-too-long worked with authoritarian regimes. Anyone who, too-often-andfor-too-long, backs the wrong partners without criticizing them creates her/his own reputation. Only having a strong moral vision does not per-se result in having moral influence.
- 2. Going back to their origins, many NGOs working on development issues were, from the outset, linked to economic liberalism (perhaps also to feminism and religion).
- 3. Coming from a moral-theological perspective, these civil society organizations stand for securing 'civilized social contracts'; they thus further tolerance and plurality in thought. Nothing wrong with that. But perhaps the time is over for this path, because, on the basis of existing socio-economic inequalities and widespread HR violations, much of civil society itself contributes to the reproduction of these inequalities and the persistence of these violations.
- 4. So, the question is whether, today, the NGO concept has the potential to deliver the structural and HR changes needed under the current 'conditions-of-Globalization'. These conditions are destroying livelihoods. Globalization is neither a natural process nor an inclusive one; it is rather a planned project, and one of exclusion. More than anything, Globalization is completing a project of recolonization. Growth through Globalization is importantly based on the theft of TO SJC, SDR, HT, HT, Vog, _ whorare your knows.
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people's resources, knowledge and economies. In the Globalization paradigm, the protection of people and the protection of nature are replaced by corporate protectionism. The rules of this imposed market- competition-dogma simply transform all aspects of life into markets. (V. Shiva) Moreover, social and employment concerns are never brought to the forefront in the process of Globalization. Globalization does not create jobs; as a matter of fact, it is a hotbed of anti-union activity.

- 5. Under Globalization, change creates both (a few) winners and (an army of) losers. It therefore behooves NGOs (now being euphemistically renamed civil society organizations by the World Bank) to work on strategies to revert this process and to find ways to work with the current losers in interventions that more proactively distribute the benefits of change more equitably.
- 6. Because of this, there are those who now dissociate themselves from the NGO concept and opt for a more radical and militant perspective: one of socialmobilization-cum-political-consciousness-raising (a-la-Paulo-Freire). Where in this continuum would you place yourself?

Claudio Schuftan, Ho Chi Minh City claudio@hcmc.netnam.vn

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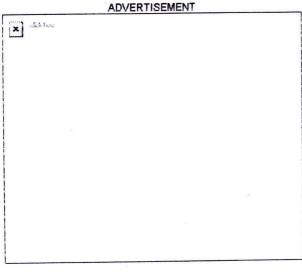
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PHA-Exchange is hosted on Kabissa - Space for change in Africa To post, write to: PHA-Exchange@lists.kabissa.org Website: http://lists.kabissa.org/mailman/listinfo/pha-exchange

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PHM-Secretariat

From:

"Abhay Seema" <abhayseema@vsnl.com>

To:

<pha-ncc@yahoogroups.com> Monday, August 02, 2004 7:31 PM

Sent: Attach:

The Right to Health approach MFC paper.doc

Subject:

[pha-ncc] Article on the Rights based approach to Health Care

Dear Friends,

I am attaching an article on exploring the 'Rights based approach' towards strengthening people's access to health care, which has been published in the recent issue of the MFC bulletin. Some of the pitfalls and cautions we may keep in mind while adopting the Rights based approach are outlined in this article. I look forward to your critical comments and ideas.

With regards,

Abhay

Abhay Shukla

B-1 Nilgiri Apartments, Karvenagar, Pune 411052

Maharashtra, India

Phone: 020-2546 5936

Visit the Jan Swasthya Abhiyan and People's Health Movement websites:

www.phmovement.org/india and www.phmovement.org

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Exploring the 'Rights Based Approach' for a Renewal of Public Health

- Abhay Shukla

Among most health activists, there is a broad consensus about the need for strengthening public health, and for greater accountability of the public health system. However, how to practically move towards this goal in the real situation, at local, state and national levels is a matter that needs to be worked out in practice. This is both a question of strategy, and also relates to our broader perspective about processes for social change.

I would like to suggest that adopting a 'Rights based approach', in the form of building initiatives for the 'Right to Health and Health Care' should be seriously explored for its potential to increase popular awareness about entitlements in the health sector. Such an approach can put pressure on the public health system to perform better, and to make it accountable. We can use the Rights framework to also address the issue of quality of care and social regulation of the private medical sector. Such an approach can also have wider social implications and linkages. But along with the possible strengths of such an approach, some of its limitations and pitfalls have also been discussed in this article, with the aim of trying to clarify ideas and to refine strategies for the health movement in the coming period.

Our approach - Right to Health; one major strategy - Right to Health Care

It need not be reiterated that achieving better health for any population is dependent not only on quality health care, but equally importantly, on assured food security and nutrition, safe water supply, sanitation, healthy housing, safe occupational and environmental conditions and other conditions necessary for healthy living. Keeping this in mind, it is necessary to define and distinguish between the 'Right to Health' and the 'Right to Health Care'.

Let us start by specifying that when we talk of the 'Right to Health' we actually mean not the 'Right to be healthy' but rather

'the Right to a variety of facilities and conditions necessary for the realisation of the highest attainable standard of health (ICESCR, General comment 14).

another similar definition of 'Right to Health' may be

"The right to the highest attainable standard of health in international human rights law is a claim to a set of social arrangements - norms, institutions, laws, an enabling environment - that can best secure the enjoyment of this right. (WHO)

It is clear that achieving a decent standard of health for all would require a range of far reaching social, economic, environmental and health system changes. There is a need to bring about broad transformations both within and beyond the health care sector, which would ensure an adequate standard of health. So to promote the **Right to Health** would require action on two related fronts:

- Promoting the Right to underlying determinants of health
- Promoting the Right to Health Care

The first, the Right to Health determinants (to use a short term) is in effect a spectrum of Rights, a set of rather diverse Rights to various services and conditions necessary for health. Many of these services and conditions (such as education or housing or environment) are not particularly amenable to direct actions by actors in the health sector (because of their lack of expertise and mandate), despite their undoubted importance for health. Agencies

engaged in the health sector may not be able to deal with most of these issues on their own, but they could highlight the need for better services and conditions, from a health perspective. Thus the role of health sector organisations in addressing such determinants may be to strengthen and substantiate demands, to advocate and support other agencies working directly in these areas, to help bring about relevant improvements.

Regarding the second, the **Right to Health Care**, we would accept that given the gross and unacceptable inequities in access to health care and inadequate state of health services today, we need to work to ensure access to appropriate, rational and good quality *health care* for all. This would involve reorganisation, reorientation and redistribution of health care resources on a societal scale. The responsibility of taking forward the issue of Right to Health Care lies primarily with agencies working in the health sector, though efforts in this direction would surely be supported by a broad spectrum of society.

With this understanding, I would argue that the overall approach of health activists might be the 'Right to Health Approach'. Within this framework, establishing the Right to health care appears as one major strategy and an imminent task, to be taken up by organisations in the health sector, within the broader context outlined above. Simultaneously, health activists should seek to link with movements for allied Rights such as Right to food, water, housing, employment – ultimately leading to a widely and strongly felt demand for an alternative system, which could satisfy all these rights more effectively.

In the remaining part of this paper, I will focus on the Right to Health Care, to be considered within the framework of the broader understanding of a Right to Health approach.

The Rights based approach – attitude towards public health system and private medical sector

In this paper, I have not dealt with the detailed content of the 'Right to Health Care' since this has been dealt with to some extent in my paper 'Right to Health Care – moving from idea to reality'. However, it seems important to make one clarification here. When health care rights are taken up as a form of resistance to weakening of the public health system, naturally the demands would be focussed on the public health system, especially in the initial phase. The framework and demands we raise would relate to strengthening the Public health system, under peoples monitoring. It is from the Public health system that we can demand a set of comprehensive health services, since it runs on taxpayer's money and is accountable to all of us. There are comparatively clear population based norms, mandated levels of facilities and at least a nominal goal of universal coverage. So as we press for the legal and social right to certain basic health services, the Government would be pressurised to strengthen and reorient the public health system, in order to deliver these services.

However the repeated experience is that when we make some general complaints about lack of proper health services, the standard response from Government officials is that 'our systems are fine, we are giving all the services, and if there is some minor issue we will solve it'. We are handed out some statistics about number of PHCs and immunisation coverage etc. etc. This hides the fact that the public health system is being weakened day by day, and people are often not getting even bare minimum services of adequate quality. So if we are to effectively challenge this situation from a Rights-based approach and even get legal support for our argument if necessary, we have to document various actual cases where people have been denied required health services from the public health system, and present this as a

widespread, serious human rights violation. This building of pressure would of course always be accompanied by the demand for strengthening and accountability of public health services.

Notwithstanding the fact that we would sharply point out weaknesses in the public health system, this does not mean that we exonerate the private medical sector, or that we promote privatisation of health services. In fact we do need to assert that citizens have certain rights concerning private medical services; to start with we should demand regulation of the quality and standards of private care, and care according to standard treatment guidelines. Regulation of costs of care is a more complex issue, which may be taken up as a subsequent step. New laws and regulatory mechanisms are required for this (for example in Maharashtra due to prolonged efforts by health activists, along with a favourable attitude of the Government, a modified act to regulate clinical establishments has been drafted.) We need to think of appropriate strategies to raise the issue of people's rights concerning the private medical sector in the coming period, and link this with specific demands for regulation.

Another related issue concerns irrational or unnecessary health care, including public health interventions that are unjustified from a socio-epidemiological perspective (such as the proposed universal Hepatitis-B vaccination). The Right to health care obviously implies the right to rational health care, and not the promotion of medical consumerism or overuse of medical resources. In fact it would encompass the right to freedom from irrational or unnecessary medical procedures. As we specify the concrete content of the Right to Health Care, we may keep these issues in mind.

In short, raising the issue of Right to Health Care would imply as the first step, demanding quality health services from a significantly strengthened and more accountable public health system, combined with effective regulation of the private medical sector. This should subsequently lead to the Right to Health Care becoming a fundamental right, and the operationalisation of a system for Universal access to Health Care over a period of time. The detailed content, mechanisms for operationalising the Right to Health Care and universal access systems are issues that require detailed discussion and working out, which could take place in MFC or broader platforms like Jan Swasthya Abhiyan.

Stages in development of the health rights approach

The utility of the Rights based approach changes with the level and stage of any movement. I would suggest that the movement for health rights might develop through three successive (though overlapping) stages:

- o Today, the fight for Health care Rights is primarily a form of *resistance* against withdrawal and weakening of public health services. Demanding the Right to Health care can form the basis for struggles at various levels, against denial of health care and user fees which form a barrier to accessing care. Asserting rights can help people to protest against poor quality of care and to oppose various forms of discrimination related to health services. Along with many others, the SATHI team of CEHAT has been regularly collaborating with people's organisations to develop such processes, as a part of various initiatives across the country.
- o Gradually, the Rights framework should also form the basis for a comprehensive policy critique, exposing neo-liberal health policies. We can demonstrate how these policies are responsible for moving from a welfare state to a market driven health system, and hence are responsible for denial of an entire range of health rights. Asserting the Right to Health

care as an overall approach can become the logical basis for demanding a system of Universal access to health care.

o Further, we may want to use the Rights approach as the basis for *counter-hegemony*, challenging the entire dominant conception of the 'Market oriented approach' to health care. Building counter hegemony is a process by which oppressed groups or classes not only challenge the dominant social framework, but also concretely develop and offer an alternative system to reorganise society. Let us examine this in some more detail below.

Counter hegemonic action: Rooted in the present, reaching towards the future

In the era of globalisation-liberalisation, ideas like 'leave it to the market', 'the government cannot be expected to do everything', 'the private sector is more efficient' etc. are emerging as dominant ideas. These ideas, centred on the 'Market oriented approach' can be considered as part of the ruling class hegemonic framework, and are accepted even by a large section of the middle class and intelligentsia. To counter this, and to win over an increasingly large section of society to the idea of a different, equitable and just social system, we can take the basis of the 'Rights based approach', as a form of counter-hegemony. In other words, one way of countering the ideological dominance of the market, may be to publicise the need for the establishment of various rights.

Counter hegemonic action may consist of asking for changes that are viewed by the majority of people as justified, even mandated by the Constitution etc. but might not often be implemented in practice. Such demands can gather strong popular support, and shift the onus of non-performance onto the system. Even if such demands are partially fulfilled, the continuous expansion of the sphere of Rights throws up ever-newer demands and continues the movement. Such action builds upon a component of people's present consciousness, namely the widely held belief that certain basic rights are justified, but can reach far into the future, by strengthening the movement for an alternative society.

In this context, we can start from entitlements in the existing system, which are universally recognised as being 'justified', such as the Right to Life which implies the Right to Health Care. We can ask, why these are not being fulfilled, and can suggest how these rights can be fulfilled if systems are organised in an alternative way. For example, asking for a system for Universal access to health care, (along with Health Care being made a fundamental right) is an idea, which would be generally regarded as justified by most ordinary people. We can build a campaign based on such a counter-hegemonic demand, which may command broad support, even from a section of health care workers and professionals. Such a campaign may achieve concrete gains for people, and may also expose the system in certain other respects. If certain political forces oppose such a proposition, the real character of such forces standing for the 'Market centred system' becomes exposed, and people can mobilise for change. However, if the demand is accepted in part, this opens the space for some concrete improvements in people's lives and at the same time, through monitoring and accountability mechanisms, can give people greater power locally. Hence counter-hegemonic demands can form a bridge between a seemingly hopeless present and a projected, detached 'ideal' future that may be viewed by people as a good idea, but unrealistic. Being able to fight for and achieve real changes, here and now, enables people to shake off pessimism ("nothing will change") and can provide hope, while opening the way for more far-reaching transformation.

Usually, the state would not deny the demand for such a Right directly, but may seek to dilute, water down, appease such demands or even try to satisfy them in a 'pseudo-progressive' form by retaining the words but taking out the substance. In such a situation, we should work for appreciable improvements in the form of achieving certain rights, expose

illusory programmes, and keep emphasising the larger aim and move towards a *progressive* expansion of rights. With each step forward, if people become more capable of asking for their rights, of monitoring the system and understanding the need for further changes, then we may consider this to be moving ahead.

Some potential shortcomings of the Rights approach to Health

The Rights based approach has certain obvious pitfalls, which should be recognised and as far as possible avoided, whenever such an approach is adopted:

- If the struggle for health care rights is limited to specific local rights (such as the availability of certain services, medicines etc.), this may pit people against the local providers (e.g. the PHC doctor or ANM) but may leave the state and national level policy makers and the global actors unscathed. Keeping this in mind, moving from resistance to comprehensive policy critique is important. Continuously pointing out the larger links and generalising the demand for health care rights beyond just local demands would increasingly bring the main decision makers into focus. Also, we may attempt to build bridges with the lower level functionaries in the public health system, and document the obstacles they face in providing services, to avoid targeting them and to raise our 'gun sights' towards the real decision makers.
- A narrow interpretation of the Rights based approach may be viewed as a 'non-political' approach if confined to a limited interpretation of a single Right ("All we are saying is give health a chance"). People may interpret it as the demand for specific improvements in one sector, while leaving the overall socio-political system intact. Here again, moving towards a counter hegemonic process where struggles for various rights converge and strengthen each other, and begin to question the system from various angles, is a process that should be attempted and should emerge over a period of time.
- As mentioned above, the demand for rights may be partly met by introducing certain reforms, and an attempt may be made to co-opt this demand as 'good governance'. Even an international agency like the World Bank may support certain limited, local 'rights' in the form of increasing accountability, checking gross corruption and so on. The coalition which has been built up to demand a certain right may be divided about whether to accept certain partial, at times even tokenistic measures being implemented by the Government. Here again, judiciously accepting genuine implementation of rights, while exposing tokenism and continuously pushing for more extensive changes is a matter of strategy, which needs to be debated and worked out in each particular situation.

Some strengths of a Rights based approach to Health

Despite these potential pitfalls, there are a number of strengths in the Rights based approach, which can make it an effective tool for the health movement, to ensure people's access to health related entitlements. Some of these features are:

- A simple slogan like 'Right to Health Care' can be comprehended, at a basic level, by anyone from an ordinary 'person in the street' to a WHO official. The rights language has a strong universal appeal, and can help a much larger mass of people, beyond health experts and activists, to relate to the basic issue and get involved. The rights approach can help us link somewhat complex issues of health policy with a demand that can be taken up by people anywhere, and considerably broaden and strengthen the health movement.
- The health rights approach empowers individuals, communities and organisations, enabling them to demand in a specific way, particular health services and facilities. Once

grasped in its essentials, this approach can be wielded by any person or collective, and becomes a source of strength and bargaining power.

- The health rights approach focuses on functional outcomes, and measures all policy changes or declarations in terms of what people actually receive in terms of real entitlements. The rights approach can effectively challenge the claims of the health officials that "we have so many health centres, we are spending so much money, we have good policies" etc. by pointing out the violations of health rights as long as they continue to occur.
- When the idiom of health rights becomes part of the overall discourse, automatically
 health services become understood as important public goods, to be universally accessible,
 distinct from commercial goods or services to be purchased in the market. This is an
 important paradigm shift, helping to push back the dominance of the market approach to
 health care.
- Rights lend themselves to expansion and universalisation. Once certain rights become established, they become a precedent for other groups or marginalised sections to demand similar rights. The rights approach naturally strengthens the claims of the most disadvantaged and vulnerable sections of society, and helps us both to challenge discrimination and to ask for attention to the most deprived.
- Rights once granted cannot be easily reversed. While policies and programmes may be changed by new governments, sometimes leading to weakening of services, once the Right to certain services or facilities is established, it would be very difficult to take away this right.
- The rights approach talks in terms of obligations and violations, thus placing the responsibility to deliver on the system. The beneficiaries are transformed from 'supplicants' to 'claim holders'. When a right becomes a legal entitlement, any individual or group that has been denied their right can institute legal action, and even a few such actions have a much wider effect, in ensuring that all facilities deliver the services.

Some pointers we could keep in mind while adopting the Rights approach

Finally, given the potential pitfalls and limitations of the Rights approach, we could keep in mind some of these pointers:

- The Right to Health Care would be realised in phases, and perhaps only to certain extent in today's social system. However, we need to work for a progressive expansion and deepening of this right over time, rather than being content with partial reforms. We should continuously establish linkages with the systemic, structural and policy issues that underlie the violation of the Right to health care. This could pave the way for demanding systemic changes, and not just 'making the existing system work'.
- We may adopt the rights-based approach to continuously push for improvements, but should try to steer clear of reformism. The difference between reformism and a radical approach, based on popular pressure and pro-people advocacy, is the question of where power, initiative and decision making lies. Since 'Reforms are changes introduced by the powerful' (Chomsky) as a top-down process, what is given from above may never reach below, it may reach in a much diluted or distorted form, or if given today may be taken back tomorrow. On the other hand, when changes take place due to popular mobilisation and the pressure of public opinion, and where people are aware of their rights and actively demand these, the changes are more likely to be actually implemented, sustained and thoroughgoing. Ultimately, one of the major strengths of the rights approach is that it takes the debate out of the circle of 'experts' (even if the debate is between official versus pro-people experts) who may continue to argue about policies, and places ordinary people, who can relate to certain

rights and demand them, on the stage. The touchstone of change is no longer who 'wins' the debate, but whether the change leads to real improvements in people's lives by ensuring them certain entitlements, which they can ultimately fight for, even without support from experts.

- In this context, any changes that we seek to bring about should strengthen the power of communities and people's organisations in being able to demand accountability of health services, and in being able to negotiate for services as a right. In the process of a campaign, even if some representatives of the movement might be involved in lobbying and developing a framework for alternative intervention, the larger mass of activists and people should retain their freedom to 'criticise from outside' and to act as a strong pressure group to push for more thorough changes and to ensure effective implementation.
- Finally, while demanding health rights, we should remain aware of the context of our dependent capitalist system, in the larger setting of globalisation liberalisation processes. Over a decade of virtually untrammelled liberalisation has pushed the social sector in this country to the wall. Yet paradoxically, the very weakening of the social sector has raised the awareness of social sector rights, since 'when policies weaken, the demand for rights gets strengthened'. And fortunately, the ordinary people of India are once again teaching their rulers a lesson that the needs of common people cannot be indefinitely ignored. Through many events large and small, the apparently invincible tide of liberalisation may be turning, even if only a little. Against the mighty Goliath of globalisation, David may be standing up at last.

And so the way ahead is difficult, but the outlines can be seen - the struggle for the Right to Health and Health care has to be strengthened, and linked up with the struggles for various other basic rights. The struggle for health rights would develop as part of a spectrum of movements for various rights, which together point the way towards the goal of social transformation. Because, despite the proclamations of certain worthy scholars, there is no 'End of history'. Though we have many more lessons to learn, and many more struggles to wage, we can look forward to a time when history will be made once again.

About the KFHR (Korean Federation of Medical Groups for Health Rights)

- The KFHR (Korean Federation of Medical Groups for Health Rights) is a joint organization of 6 NGOs representing 40,000 hospital workers, about 2,500 various medical professionals, and activists for workers' health right.
- The NGOs forming the KFHR are organized in 1987, the period of Korean renaissance of social movement. The KFHR have struggled for the reform of the national health insurance system, organized social movements against privatization of public health system, demanded people's right to the accessibility to essential medicines, and actively participated in anti-war movement.
- In year 2003, the KFHR sent a medical aid team to Iraq from May to July, and held the Asian Health Forum 2003 'People's Health Right against WTO/Globalization' in September.
- We are preparing two testimonies in the IHF 2004, which are 'The Medical Situation of Baghdad, Iraq', and 'Gleevec Campaign against Novartis, a pharmaceutical TNC'.
- As a program of the WSF 2004, the KFHR is preparing a workshop with the title 'The Impact of the U.S. Military Bases and People's Struggle Against It: 5. Korea, the Philippines, Japan, and Iraq'. It will be held at room A-14 at 9:00-12:00A.M., January 19.
- To contact us, please mail us, call us, and visit our website(though the contents are written in Korean).

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The Impact of the U.S. military Bases and People's Struggle Against It S. Korea, the Philippines, Japan, and Iraq

The U.S. operate a vast array of foreign bases manifesting many social and environmental problems. After watching the gross injustices taking place in the Philippines, Vieques, Japan, and Panama, and now we have faced people's sufferings and resistance against US army in Afghanistan and Iraq.

As American military hegemony continues to grow like a cancer across the globe, there will be more and more places in need of international solidarity while dealing with U.S. base issues.

We will have reports from the damage by a firing range in Maehyangri, Korea, the US base in Okinawa, Japan, and Subic, the Philippines. In addition, KFHR report about the Iraq survey result which was done May to July 2003. Asia, as a most threatened region by U.S unilateral militarism after September 11, we would like share our pain, urgency and furthermore solidairy and hope. We need stop the U.S and Koreans look forward to being a part of such efforts.

Date: January 19, 2004

Time: 9:00-12:00

Place: A-14

Organized by KFHR(Korean Federation of Medical Groups for Health Rights)

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1. Background

From April to July 2003, the KFHR provided medical aid in New Baghdad area, but this was not a project made by the KFHR alone. Just after the start of the violence in Iraq, South Korea was sizzling with anti-war demonstrations and campaigns to raise money for the Iraqi people. In spite of these activities, the S. Korean government was planning to send army to Iraq. To lead the public opinion against sending army and to help the Iraqi people, the Hangyore Newspaper and the KFHR decided to send medical aid team to Iraq.

2. The situation in Iraq

Iraq had had quite effective public health care system until the early 1980s. But with a series of wars and economic sanctions for 13 years, the social infrastructure of Iraq crumbled down. After 1991, the budget for medicine fell to 1/4, neonatal death rate rose in a steep curve, chronic shortage of medicine and medical equipments, and leakage of medical professionals to other countries all led to the instability of medical system. The invasion of coalition force was a large blow on this fragile system.

3. Medical aid

Before the end of war, the main task was to supply intravenous fluids and anesthetics to the hospitals of Baghdad and gathering information of the medical status.

In May, the war ceased and we focused to rebuild primary health care centers in Al Mashtel area. Medical team provided medical care to about 200-300 patients every day, and medicine was supplied to several health care centers in this area.

4. Survey

The purpose of our activity was not only to provide medical aid, but also to work as a part of anti-war activity. We've conducted some survey to evaluate the nutritional status and the psychiatric stress on children who've suffered two wars and long lasting economic sanctions.

By the survey on psychiatric stress, it became obvious that even though children seemed cheerful and smiling, they were suffering from serious stress. More than 80% of children replied that they feel lonely and unhappy; about 90% of children were fearing of death of their families or themselves: 85% of children felt safety only when

they were with adults; and 80% replied that they think something bad would happen and feel unsafe if they are at unfamiliar places. It has become impossible to expect Iraqi children of childlike curiosity and adventurous spirit any more.

5. Remaining Issues

In the standpoint of scale and effectiveness, the activity of KFHR is obviously insignificant. We think our effort was just pouring a bucket of water on a dry desert. However, we would like to find some meaning on our activity.

First, instead of just delivering medicine and doctors, we tried to help Iraqi people help themselves and tried to draw an up-to-date picture of the medical system.

Second, many Korean anti-war activists and other local activists helped the KFHR in Iraq, and thanks to their effort, we could settle many strategies that the KFHR would follow in the future activities.

Third, according to our evaluation, while major hospitals were filled with staffs and medicines, local primary health centers had difficulty to find medical staffs and medicines. We concluded that reconstruction of the primary health care center would be the most urgent task to improve the health status of Iraqi people.

As a conclusion, providing medical aid AFTER war is not sufficient. The more important thing is to PREVENT war. Therefore, we concluded that while providing medical aid to the people in need, we should try to gather information of the impact of war on people's health and provide it as an evidence of anti-war movement, to prevent the war in the future.

"Gleevec campaign against Novartis"

1. From Asking for Drug

1) About Gleevec

Gleevec(STI571) is the only known effective therapeutic agent for CML(chronic myelocytic leukemia) except for BMT(bone marrow transplantation). As BMT is available for only a small portion of CML patients. Gleevec is the only effective oral medicine that CML patients can depend on.

2) Patients Start to Organize

In December 2000, the news about a miraculous drug called Gleevec reached to the CML patients through the Internet. Patients pleaded for early approval and marketing of this medicine. In July 2001, Novartis launched Gleevec in S. Korean market.

Patients waited for its emergence in the market with hope, but this hope turned into despair when they found out the price of Gleevec was about 19 USD for each capsule. An ordinary CML patient have to take 4 to 6 capsules each day, which costs about 76 to 114 USD every day, 2280-3420 USD every month to survive.

This ignited the leukemia patients to unite and they formed the 'Korean Association of Leukemia Patients(KALP). The KALP and the KADAG¹ asked Novartis to reduce the price of Gleevec, asked the S. Korean government for more coverage of National Health Insurance(NHI) for cancer treatment, and also for approving compulsive license to produce Gleevec.

As a result of struggle that lasted two years, the patients received the promise of more coverage of the NHI, including more coverage for the medicine, and more indication for applying the NHI. On the other hand, Novartis didn't step back even one step to uphold the 'Worldwide-Single-Price Policy'.

2. To consideration of so many aspects

During the struggle and arguments, the members of KALP and KADAG encountered many facts about the development of medicine, the unreasonable process of pricing, and rethinking of priority in right to health vs patent right.

1) Policy on Pricing

The target markets of pharmaceutical TNCs are the highly developed countries which occupy 80-90% of all drug markets. As a result, the price is based on the affordability of those countries, but this is too expensive for people of all the other countries.

Especially for a newly developed medicine like Gleevec, the global single price is so high that even British and Australian government hesitated to approve insurance coverage for Gleevec. In the case of S. Korea, the price of Gleevec is based on the average price of seven leading countries: the USA, Britain, Germany, France, Swiss, Japan, and Italia, whose GDPs are several times more than S. Korea.

According to the Novartis' website, in year 2002, Gleevec's sales topped 615 million USD, making it Novartis' fifth biggest product in the second year of its market emergence.

In desperate effort to get the medicine, Korean patients found a generic brand named 'Veenat' produced by Natco pharma Ltd., an Indian pharmaceutical company. All were stunged by the fact that the price of Veenat was only two dollars per capsule!

2) Patent Right vs Right to Health

Novartis and many other pharmaceutic TNCs claim that they have invested a lot of money to develop such medicines. But in case of Gleevec, it was issued as an orphan product, the company was benefited by reduction of tax, shortened clinical test period and approval for sale because patients pleaded the government to shorten the trial period.

As we see in the Novartis' website, Novartis has already regained the money they've invested to develop Gleevec. The cost price of Gleevec is not so expensive as we see the price of Veenat, and Novartis still has the global exclusive patent for 13 more years.

In March 2002, the KALP and KADAG submitted a petition to the National Human Rights Committee claiming that the National Health Insurance(NHI) system is discriminating CML patients by several reasons, and therefore infringing on their right to health. This was the first appeal in S. Korea that patients claimed for their health as a human right.

In the struggle over Gleevec, the patients are not asking the pharmaceutical companies to give up. They are just asking for a more reasonable price.

There are many other desperate patients in the world who are suffering from various diseases and expensive medicines. Especially, the medicine for Malaria, Tuberculosis, and HIV/AIDS are of main concern.

If we don't reconsider the policy on pricing and if we don't focus on the accessibility to essential medicine as a basic human right, this list of desperate patients will grow longer and longer.

L-6.

Stop Oppressing the Poor In the Name of Beggary Prevention

Withdraw Draconian, Anti-Poor Beggary laws

Bharat Dogra

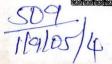
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"The society which cannot provide for social security ensuring satisfaction of minimum needs has no moral authority to arrest persons for begging out of sheer helplessness."

- Bombay High Court (Commission on Beggars Act, 1990)

Massachusetts's highest court has held that to prohibit begging is to prohibit individuals from "engaging with fellow human beings with the hope of receiving aid and compassion."

(424 Mass 918-1997)



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A widely recited doha of Kabir implores people never to torment those who are already weak and distressed. In present times, India's beggary prevention laws and their implementation provide one of the worst examples of tormenting the poorest, most vulnerable people.

Despite the ancient tradition of charity and alms-giving in India which created conditions in which some of the most venerated saints chose to obtain their subsistence by asking for alms, it is strange that the modern Indian legal system has gone to the other extreme of criminalising not only begging but even the mere suggestion of begging. For example the Bombay Prevention of Begging Act (1959) defines begging in such a broad way that any poor and homeless person can be listed as a beggar, and this listing in turn can lead to imprisonment for a long time in the most difficult conditions imaginable.

It is bad enough for law to criminalise all forms of begging, it is perhaps even worse that even those who do not beg are also arrested under these laws in large numbers. What is more, the custodial institutions built around these laws are generally run in such a way as to inflict the worst suffering, humiliation and in many cases even torture on their inmates. Infact violation of basic human rights is seen at almost all stages of these anti-beggary acts.

It was therefore a case of a long-felt need being fulfilled when a 'National Consultation on Urban Poor With Special Focus on Beggary and Vagrancy Laws' was organised on July 15 and 16 in Delhi. Ashray Adhikar Abhiyan, an organisation working for homeless people in Delhi (which has achieved much in a short time)

teamed up with Action Aid and Indian Social Institute to organise this much needed consultation.

A particularly moving aspect of this consultation was the testimony of several persons who had actually suffered due to the highly distorted anti-beggar laws and their equally arbitrary implementation.

Gaur Nisha was rushing on a New Delhi Road to fetch medicine for her daughter who was prone to having fits. Two other children accompanied her. Suddenly a group of policewomen swooped on her and pushed her into a waiting van. Nisha shouted again and again that her sick daughter is waiting, but her cries were ignored and the van drove away.

Just a few metres away Zainam waited endlessly for her mother to come. The minutes turned into hours and hours into days but mummy did not come. She wandered aimlessly here and there, her fits troubling her but probably also protecting her from persons with wrong intentions.

Meanwhile Nisha was taken to a place which she learnt later was a beggars home. Here whatever little money she had was snatched away and she was given a heavy work load. She also saw a woman being beaten in the most cruel way and so she did not dare to protest.

When she finally managed to send a message of her confinement to a friend and efforts were made to bail her out, she rushed to find her daughter. For once luck was on the side of the troubled mother as she was able to find her daughter - in a bad shape with several layers of dust and dirt but safe otherwise.

Anoop was selling garlands in a Delhi market when

a policemen asked him to take one garland to a waiting van. As the unsuspecting youth, a newcomer to Delhi from Faizabad approached the van to give a garland, he was asked instead to step into the van. His garlands

were thrown away and he was driven away.

When he did not return till late evening his parents set out in search for him. Some shopkeepers told them that their son had been taken to Seva Kutir after being accused of being a beggar. This poor household had to incur a heavy debt to get their son out on bail.

Social workers working with homeless people and lawyers providing legal aid at beggars' homes have hundreds of examples of people who have been treated very harshly and unjustly under the existing beggary prevention laws in Delhi and elsewhere. Human rights are violated at every stage. Generally poor helpless people picked up arbitrarily are not informed where they are being taken. They may be imprisoned for one to three years (or even more if they have been brought a second or third time) for the supposed 'crime' - real or false, of begging. The places where they have to live out this sentence are deprived of the most basic needs. Inmates are beaten up frequently and given huge workloads. Women face the additional hazards of sexual exploitation. Many of them are unable to contact their families in far-away villages. Their families live in constant tension of what may have happened to them. Some of them become so depressed that they lose the will to communicate with outsiders. When they emerge from their dismal sentences, many of them cannot continue whatever precarious livelihood they pursued earlier and do not have the heart to tell family and friends that they had been confined all the time to a beggars'

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home

After hearing the testimonies of people who have actually suffered under the anti-beggary laws and the views of several legal luminaries and social activists, this national consultation concluded firmly that anti-poor beggary laws should be scrapped. The only aspects of begging which need to be curbed relate to the various types of forced begging in which children or even adults may be kidnapped and/or injuries may be inflicted on them and they are then forced to beg to bring profits to gangsters. Strict actions against such forced begging rackets can be taken under I.P.C. Similarly any other aspects of forced begging/extortion can be taken care of by other legal provisions. There is absolutely no need for separate beggary prevention laws, particularly of the kind which criminalise all begging, (as distinguished from a small part of forced begging). These anti-poor laws should be scrapped along with the custodial infrastructure mainly beggar homes (Delhi has nearly a dozen of these) they have needlessly created. These wasted efforts and funds should instead be channelised to providing better health service to homeless and destitute people as well as to beggars. Several aspects of such an effort including better mental health service and a humane approach to care of leprosy patients were discussed at this national consultation.

To have a better understanding of this muchdistorted issue, it may be helpful to examine it in three parts - (i) the real condition of beggars and begging in the context of urban India (ii) the elitist perception of this issue as also reflected in the policies of the government and (iii) suggestions on how government policies should be changed to tackle the real issues in such a way that most vulnerable people get real help and the involvement of the people can be obtained in such an effort.

I - Understanding the Real Condition of Beggars

Even according to government's own statistics, crores of people live below the poverty line. Even if we ignore the non-official estimates (which are on the higher side) and go strictly by official estimates, 260 million people in our country do not have incomes to access a minimal consumption basket which defines the poverty line. India has 22 percent of the world's poor. Every third child born in India is under-weight. Around half of the pre-school children suffer from under-nutrition. More than half of India's women and children are anaemic. During the last 10 to 15 years there were cutbacks in some of those schemes which the government regards as the most crucial planks of its poverty alleviation effort.

The fragile subsistence of poor people can be shattered by the all-too-numerous (and increasing) calamities like floods, droughts and accidents. The incidence of occupational accidents and diseases is known to be very high. The number of people suffering from diseases which render the body incapable of any hard work is very high in India. The plight of widows and deserted women is very bad. Aged persons, particularly when they are diseased or disabled, face increasing neglect from their families. The number of physically and mentally challenged people is known to be much higher than the official estimates. The overwhelming majority of poor people are deprived of even minimum provisions

for social security. Keeping in view this situation should it surprise anyone if millions of people have no other choice but to appeal to the compassion of more fortunate fellow human beings to meet their subsistence needs?

Recently Action Aid conducted a study to understand the real condition of beggars. This study was based on interviews with 1248 beggars, 50 officials and 28 alms-givers. This study was conducted in 9 cities of four states. - These cities are Jaipur and Aimer (Rajasthan), Chennai and Madurai (Tamil Nadu), Patna and Gava (Bihar) Allahabad, Lucknow and Varanasi (Uttra Pradesh). According to a presentation of this study by Subrata De, this data shows that almost every beggar (99% among men and 97% among women) get into beggary due to poverty. Almost all the beggars (85%) used to have an earning below the poverty line annual family income (less than Rs. 8000-9000) before getting into this practice. Out of that 25% people got into beggary because of poverty along with disability, disease, old age etc.; and 15% faced family problems due to poverty.

None of these people had agricultural land or assured income from sharecropping. Inability to sustain the family system led quite a large majority of people (more than 75%) to leave the rural livelihood and come to urban areas. Considerable portion of people could not do manual work due to disability, physical and mental, (76% among men & 55% among women) and old age (52% among men & 43% among women). Only one-fourth (27%) people were literate. Out of that only 16% people had gone to school. Within the school going group more than 70% dropped out soon after getting

into secondary level. Little more than 1% passed class it surprise anyone if millions of people have no of 01

This study found the daily income of beggars ranges from Rs. 2 to Rs. 50. Average income is Rs. 26 for ablebodied men and 30 for able-bodied women. Moreover 28% women and 36% men earn less than Rs. 20 per day. Disabled and diseased people earn more, Rs. 45 for women and 31 for men and this average in the board.

People cannot take bath for weeks or wash clothes for months together. All of them have developed some health problem due to such unhealthy living. 25% money is spent on an average for toilet, bath and washing clothes and 5% for drinking water. The medical expense is very high (average 20%, but at times it goes up to more than 35% since Govt. hospitals generally do not treat them). Beggars end up paying a considerable portion of their income to police, which is included in expenditure for place of stay. Amount under this head at times go up to 50%. Almost all the beggars (94%) are forced to remain on street without shelter. More than 80% beggars have opined that police beat them unnecessarily. 32% beggars felt that beating is used for extracting money from them.

It is clear from this study that most of the beggars are genuinely needy people who have suffered much from the ravages of hunger and poverty. From a common sense point of view, there is absolutely nothing criminal about the effort of a hungry or badly deprived person to meet his or her basic needs (as well as the needs of their dependants) by appealing to the compassion of fellow human beings and obtaining small amounts of money or food from them. The criminal aspect of begging is confined to only a very small

section of beggars-where gangsters force children or adults to beg for them: It is completely unjust and is made to be a completely unjust and is

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policies based on this perception

Unfortunately eliist opinion frequently fails to recognise this real situation of beggars. This is part of a larger tendency of elitist opinion to be unsympathetic towards urban poor. For example, elitist opinion frequently opposes the housing rights of slum-dwellers and pressurises the government to demolish slums, or to shift slum-dwellers to the outskirts of the city. Elitist opinion is even less tolerant towards beggars who are described as a menace and the government is asked to somehow remove them away from the sight of local elites and tourists. Elitist opinion encourages the impression of beggars as idle people trained to earn easy money from others. This opinion also greatly exaggerates the presence of criminals in begging, while ignoring the obvious reality of millions who genuinely needs alms for sheer survival. dozen beggars homes. This is a highly

accepted by the government as the central plank of its policies towards beggars and beggary. Most of the legislation on this subject regards all begging as a crime, instead of confining the stigma of crime to only a small section of forced begging. This amounts to needlessly tormenting millions of already distressed people. Due to the unjust socio-economic conditions of the country, extreme inequalities as well as the additional burden of calamities and accidents, millions of people are reduced

to a situation that they resort to begging in cities and towns. It is completely unjust and irrational to regard them as criminals. At a time when a shortage of police force is frequently cited as an excuse for the government's inability to curb serious crime, where is the justification for using the police to chase poor helpless people? Social welfare officials are paid to promote the welfare of weaker sections. Where is the justification of using them to arrest poor helpless people?

Infact the existing laws (and their implementation) are even worse than this. In reality these are being used to arrest not only beggars but even other helpless, mostly homeless people who have never begged. This happens also in the normal course of the implementation of these laws but this is stepped up particularly at the time of special anti-begging drives when the anti-begging squads are under pressure to 'capture' a large number of beggars.

A highly unjust aspect of the existing anti-begging effort is that in many cities a huge infrastructure has been created around the implementation of beggary prevention laws. For example in Delhi there are nearly a dozen beggars homes. This is a highly corrupt system and to keep this corrupt system running a steady stream of beggars and alleged beggars are needed in these custodial institutions. Hence powerful persons develop a vested interest in the perpetuation of a highly unjust and cruel system.

At present there are about 12 beggary prevention laws in operation in the country, many of them going back to colonial times. These laws include the following - The West Bengal Vagrancy Act, 1943, the Mysore

Prevention of Begging Act, 1944; the Madras Prevention of Begging Act, 1945; the Bihar Prevention of Begging Act, 1951; the Bombay Prevention of Begging Act, 1959; the Jammu and Kashmir Prevention of Begging Act, 1960; the Andhra Pradesh Prevention of Begging Act, 1964; the Haryana Prevention of Begging Act, 1971; the Punjab Prevention of Begging Act, 1971; the Goa, Daman & Diu Prevention of Begging Act, 1972; the Cochin Vagrancy Act, 1974; the Uttar Pradesh Prohibition of Begging Act, 1975;

Some of these acts apply to a wider area than what is suggested by the titles. For example the Bombay Prevention of Begging Act (BPBA) was extended to Delhi in 1960-61 after adding some rules for Delhi.

While these laws may differ in detail, by and large the tendency is to regard beggars as criminals and thereby to call for the elimination of beggary - including begging that takes place for very genuine subsistence needs in the absence of alternative means of subsistence. Here we examine particularly one such law which applies to two of India's most important cities (Delhi and Mumbai).

The BPBA has a very wide definition of begging -

- a) soliciting or receiving alms in a public place, whether or not under any pretence such as singing, dancing, fortune telling, performing or offering any article for sale;
- b) entering on any private premises for the purpose of soliciting or receiving alms;
- c) exposing or exhibiting, with the object of obtaining or extorting alms any sore, wound, injury, deformity or disease whether of a human being or animal;
- d) having no visible means of subsistence and wandering about or remaining in a public place in such a condition or manner,

as makes it likely that the person doing so exists by soliciting or receiving alms.

Any poor, unemployed, homeless person can be picked up under this law. In practice this law has been interpreted even more widely by officials bent on fulfilling their target of 'capturing' a certain number of 'beggars'. According to this Act, any police officer may arrest without a warrant any person who is found begging. This power may also be extended to any other person (such as official of Social Welfare Department) in accordance with the rules. The police department has created a special anti-begging squad which is attached with the Department of Social Welfare at its Reception-cum-Classification Centre.

Now let's see what happens in practice when such wide powers are given to arrest beggars or supposed beggars as though they were criminals?

In the year 2000 eight inmates of Lampur Beggars Home died and 114 suffered from gastroenteritis. When news reports appeared to this effect, the Delhi High Court asked a lawyer Mr. Rakesh Saini to prepare a report on beggars' homes in Delhi and related issues. This is what he wrote in his well-documented report -

"My conscious is shocked... to learn that for a simple and unfortunate so-called offence of begging, a citizen of the country, who is a victim of circumstance for the creation of which the state and society are also responsible to some extent, can be deprived of his personal liberty and freedom and detained for a long period of 2-3 years, merely by a summary trial and thrown into a Beggars homes only to be beaten up and tortured there, taken advantage of and exploited and exposed to the risk of disease and a horrible death there.

"In most of theses institutions, a number of persons complained that they were innocent and not professional beggars and were forcibly picked up from various places in Delhi while going their way, taken to remand and classification centre at Kingsway Camp where they told the probation officer about themselves who assured them of help and redressal but did not do so. Instead, they were beaten up and tortured and thereafter produced before the magistrate. The magistrate also did not listen to them and sent them to the Beggars Home to be kept there for 1-2 years."

-R. K. Saini in the High Court Committee (HCC) Report on Beggars Homes

In another official report 'Beggar Institutions - Lampur, Narela - An Assessment report (Commissioned by the Government of NCT of Delhi, March 2001) a senior official G. D. Badgaiyan confirmed that many innocent people are arrested. Many indiscriminate arrests are due to the emphasis on fulfilling 'targets' or 'quotas' particularly during anti-begging and beautification drives. The accused are taken to the Beggars Court or Poor House Court. This report criticised the lack of legal aid in the court and the fact that the Magistrate was acting as defence lawyer, prosecutor and judge. As this report pointed out, each trial lasted two minutes on average and only five people were acquitted in 2000.

However many of the arrested people could get relief once a legal aid system was introduced at the Beggars Court and also to help the inmates of the Beggars' Homes. In recent times a large number of arbitrarily arrested persons have escaped harsh imprisonments due to the dedicated efforts of a handful

of highly committed lawyers providing legal aid in very difficult conditions and having to overcome a lot of resistance and many hindrances. In Delhi this legal aid system for beggars and alleged beggars is in place due to the effort of a Delhi Legal Service Authority (DLSA), Legal Aid Clinic (Faculty of Law, Delhi University), Human Rights Law Network and Ashray Adhikar Abhiyan. Social activists and public spirited lawyers in other parts of the country can benefit much from the recent experiences of these dedicated lawyers, legal experts and social activists in Delhi to take legal aid to the poorest of the poor in Delhi.

Even though these lawyers are able to help several distressed people almost every day, they still feel strongly all the time that this is only a temporary relief and the real solution lies in repealing the anti-poor, draconian beggary prevention laws.

Recent surveys by Ashray Adhikar Abhiyan conducted with the help of lawyers and social activists have revealed that alarming violations of human rights continue in the existing system of arrest and confinement under BPBA in Delhi. For more than 90 percent of the arrested persons, the manner of arrest had elements of coercion, deception, false promise, abuse and violence. Generally they were not told where and why they were being taken against their will, 78 percent said they were not aware of reason behind arrest. Asked about activity at the time of arrest, only 11 percent described it as begging or receiving alms. Clearly, all this cannot be tolerated in any society that values human rights. This injustice to the poorest has continued for too long. It must go - the sooner the better.

III - Alternative Policy Framework

Therefore it is proposed that

- (i) the existing beggary prevention laws and the supporting infrastructure of beggars' homes etc. should be scrapped along with funding for the same.
- (ii) These funds should be diverted to providing health care to beggars, destitutes and homeless people, with a special emphasis on mental health and leprosy. This should be a partnership of government and citizens' groups who are keen to help these poorest of the poor in our cities.
- (iii) Whenever any traces of organised begging gangsters who kidnap and maim for forced begging are found, strict action should be taken under provisions of I.P.C. Similar existing legal provisions can be used to prevent any extortion.
- (iv) Ordinary begging activities should be free from the stigma of crime throughout the country.

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The Right to Health Care is a Basic Human Right!

Towards attaining the Right to Health Care...

The Government of India has been unable to fulfill it's commitment of 'Health for All by 2000 A.D.' till now. In fact, primary health care services are becoming more and more difficult to obtain especially for people living in urban slums, villages or remote tribal regions. The condition of government hospitals is worsening day by day. Nowadays, in most of the government hospitals there is inadequate staff, the supply of medicines is insufficient and the infrastructure is also inadequate. The facilities for safe deliveries or abortions are also very inadequate. Given the fact that women do not even get adequate treatment for minor illnesses such as anaemia, services for problems such as the health effects of domestic violence remain almost completely unavailable. At the village level, there is no resident health care provider to treat illnesses or implement preventive measures. All hospitals are located in cities, and here too public hospitals are increasingly starved of funds and facilities. Thus there is lack of availability of government health care services on one hand and the exorbitant cost of private health services on the other. This often leaves common people in rural areas with no other option but to resort to treatment from quack doctors who often practice irrationally. Thus most of the population is being deprived of the basic Right to Health Care, which is essential for healthy living.

The Indian Constitution has granted the 'Right to Life' as a basic human right to every citizen of India under article 21. In article 47 of the Directive Principles of the Indian Constitution, the Government's responsibility concerning public health has also been laid down. Yet the Government is backtracking from fulfilling this responsibility. This is obvious from the fact that the Government's proportion of expenditure on public health services has been declining every successive year.

What can be done in the near future to establish the Right to Health Care?

The year 2003 was the silver jubilee year of the 'Health for All' declaration. On this occasion, Jan Swasthya Abhiyan launched a nationwide campaign to establish the Right to Health Care as a basic human right. Some of the following activities are being taken up as part of this campaign:

- Documentation of individual case studies involving denial of health care. Information is being
 collected in a specific format with the help of questionnaires. The cases where denial of health
 services has led to the loss of life, physical damage or severe financial loss of the patient are
 being emphasised. These case studies will be presented to the National Human Rights
 Commission. It is hoped that they would help us to depict the real status of provision of the
 primary health services by the government and strengthen our demand for improving public
 health services as well as help us in dialoguing with the public health system.
- Similarly, situations of structural denial of health care, where Primary Health Centres, Community Health Centres or public hospitals are regularly denying basic health services to people are being documented. Questionnaires have been prepared to help in such documentation, based on which the demand for adequate services and facilities may be raised.
- Jan Sunwais on the Right to Health Care are being organised at the local, district and state level.
 JSA linked organisations can organise such Jan Sunwais to highlight the state of public health services, and instances of denial of health care / structural denial of health care can be presented in these programmes.
- The National Human Rights Commission, in collaboration with Jan Swasthya Abhiyan, is
 organising Public Hearings on Health and Human Rights in various regions of the country from
 mid-2004 onwards. These regional hearings would be followed by a national public hearing. JSA
 linked organizations and individuals can present case studies during these public hearings and
 ask for effective action by state health authorities and investigation by the NHRC.

These are some of the steps being planned to move towards establishing the Right to Health Care. Let us join this campaign and strengthen the movement to achieve health care and Health for All!

Jan Swasthya Abhiyan – People's Health Movement India

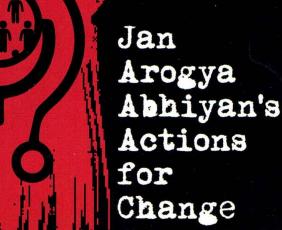
For more information visit www.phmovement.org/india or contact:

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Patient's
Rights
Campaign
in
Maharashtra





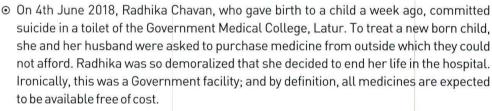
This is
a story of
Jan Arogya
Abhiyan,
Maharashtra.

For long private sector regulation as an agenda, remained confined to the policy makers and the medical professionals. Patients and ordinary citizens, who are mainly affected by the behavior of the private medical sector, were outside the realm of regulatory deliberations. The dominant narrative on the private sector was always from the perspective of the powerful medical lobby.

This situation is slowly changing. People are getting mobilized. There is a popular narrative shaping up, arising out of people's lived experience. This document is an attempt to capture the spirit and the hands-on feeling of actions that arose from the real-life efforts of patients, community, and activists.



Stories of people who have been denied health care, or were exploited by the very hospitals and doctors in whom they have confided are not uncommon in India. Some remain untold, and some are so striking that they. Here are some true stories-





Sixty-two years old Chandrashekhar Kulkarni from Mulund, Mumbai, was operated in a big private hospital for non-existing cancer. Part of his intestine was removed. Crippled for life with different complications, Mr. Kulkarni spent 20 lacs on the surgery, and when he consulted another doctor for a second opinion, he came to know that he never had cancer. He is today fighting a lone battle with the medical establishment, starting from approaching Consumer Forum to redress gross medical negligence, to Maharashtra Medical Council- which is expected to take punitive action in cases or breach of medical ethics.



• Pranju Dange was admitted with a brain hemorrhage, in the CIIMS Hospital which is a charitable trust hospital in Nagpur, on 5th July 2017. Inspite of all the documentary evidence to prove that she belongs to economically poor section of the society, and deserves free treatment as mentioned in the government rule, CIIMS denied her free treatment. Moreover, even when the Chief Minister's office ordered CIIMS to treat her free of cost the hospital refused to oblige. Her family was forced to sell their agricultural land- only source of family income, to take care of the hospital expenses. A due complaint was lodged in the Nagpur Charity Commissioner' Office, however there is no action so far.



The pain in these lines is real, and people in these stories decided to make their grievance visible and public. On the backdrop of despair, people in these stories, along with activists, are fighting back against injustice. This document is an attempt to give glimpse into Jan Arogya Abhiyan' struggle for patient's rights. It tells what we won and what remains to be own it says small victories matter; and remembering them matters too.



What are our grounds for hope for ensuring patients' rights?

No private health provider and institution can oppose patient's rights in principle. Every healthcare institution has to wear an apparent mask of protecting patient's rights. However, in a stark contradiction, when it comes to enactment of the Clinical Establishment Act- which effectively can safeguard patient's rights and regulate the private sector, opposition from the united private medical sector is fierce. In contrast, patients and communities are not organized to question the unethical and exploitative practices in the private health sector. People require a forum to get together, to share stories, build solidarity, and turn it into a campaign. We perceived this need and started to work on patient's rights.

First strategy was to use an idiom that people know, and to establish a narrative on patient's rights. So, what did we do?

■ Voting for patient's rights- Voting for better health care

Under the broad heading of "Patient's Voice, Citizen's Initiative Campaign," we organized voting for patient's rights in different parts of Pune District, from 15th June to 30th June 2017. Each ballot paper reflected what people want; it was an exercise that gave us a glimpse of how strongly people feel about patient' rights in both public & private healthcare sector, and the exploitation in the private sector, and how much they aspire for better public health services. Here is a snapshot of the voting-

- ⊙ 21351 votes were cast.
- The voting was conducted at more than 80 places in Pune district.
- ⊙ 670 people voted online.
- People from various residential societies, slums, villages, companies, colleges, self-help groups participated a very wide cross-section of society voted- there were government employees, doctors, nurses, IT professionals, unorganized sector workers, waste pickers, farmers, farm labourers, sex workers, people belonging to nomadic tribe community, truck drivers; all voted with fervor.
- In this voting exercise, three questions were asked. Should Maharashtra Government regulate and standardize private hospitals to check commercialization? Should Maharashtra Government take concrete steps to improve quality of care in public hospitals? Should Government immediately enact legislation to protect patient's rights?
- Out of the 21351 people who voted, an overwhelming 21067 (98.7%) voted in favour of bringing private hospitals under regulatory framework while 21247 (99.5%) agreed that government should take concrete measures to improve quality of care in public hospitals. 21225 (99.4%) people demanded the enactment of a legislation to protect patient's rights. This indicates that people from all walks of life are dissatisfied with current healthcare options and they strongly demand reforms in the healthcare system.









The context of voting, the sheer number of people who voted, underscored the importance of engaging with ordinary people. The campaign culminated into a public event, and the results of the voting were announced on 1st July 2017 (Doctor's Day). Noted theater personalities like Atul Pethe, activists like Poornima Chikarmane, and people from all walks of life participated in this event. The uniqueness of this event did not go unnoticed, almost all leading newspapers and electronic media reported about voting and results.

- Many people who voted, were not just there to cast a vote, but shared personal stories of denial, negligence, and exploitation.
- Voting as an idiom had struck a chord with people. They found agency and meaning in the voting and came out in large numbers. In a process, we also got a sense about the magnitude of discontent regarding existing status of healthcare services in both public health system and private health sector.
- This social churning did not go unnoticed; media covered details regarding the voting and the public event in great detail.

This campaign gave us confidence that people' power is with us. We also knew that dreams and reality are contrasting, but actions synthesize them.

What have we learnt?

Knocking the door of decision-makers: Actions for change -

Making discontent visible and public is often a first step in remedying it, the experience of voting reinforced our advocacy efforts.

14th December 2017- A rally for patient's rights and enactment of the Maharashtra Clinical Establishment Act-

The unexpected success of the voting inspired us to move forward, and we realized that time had come to engage with the ruling government and the other elected representatives to assert our demand for the patient' rights. Street protest is many times a tactic of last resort when more conventional advocacy actions fail to open up policy space. It was a time for the rally. The place was Nagpur, and the occasion was the winter session of the Maharashtra Assembly.

This was not the first time that JAA organized such a rally during the winter session of the Assembly. In December 2012, a similar campaign was organized by JAA, and follow-up protest was also held in 2013. Both these campaigns, and sustained advocacy resulted in formation of the Drafting Committee, in which Jan Arogya Abhiyan got representation, which came up with a draft bill of Maharashtra Clinical Establishment Act, in June 2014. With specific elaboration on the charter of patient's rights, district level grievance redressal mechanism, enhanced representation to civil society organizations in the various official bodies/forums, provision of dedicated human resources for implementation of the legislation in the form of Directorate of Clinical Establishment were proposed in this draft by Jan Arogya Abhiyan and included in the bill. This draft bill was significantly improved and more pro-people than the model Clinical Establishment Act passed by the parliament of India. Jan Arogya Abhiyan also insisted upon removal of non-practical and seemingly harsh provisions from the point of view of any rational, ethical doctor. Those changes were also accepted. Following endorsement from the Directorate of health services, it was accepted by the Health Minister. However, with the new government in power in 2014, and with the changed political priorities, the draft Maharashtra CEA was not adopted. Tellingly, the rally on 14th December, was also to remind government about previous commitments and the need for implementation.



Communicating through Pamphlets, Posters, and Slogans-

Side 3

Dr. Deepak Sawant @dr... · 15 Dec 17 The State Government is enacting an Act on the lines of Central Government's Clinical Establishment Act to keep control over private hospitals overcharging the patients. #ShivSena @AUThackeray Protesters at the front of the rally flashed a big placard with an unmissable cartoon of the Health Minister, with a prominent and provocative message - "Health Minister Wake Up." Over the years JAA has realized that slogans are powerful; they persuade people to think, and messages in slogans travel quickly. The rally in Nagpur was no exception. Activists and ordinary people came to join the rally. The rally culminated just before the entrance of Maharashtra legislature.

A delegation of JAA met the Health Minister of Maharashtra, Minister of the State- Health, Leader of the Opposition, and 18 Members of Legislative Assembly (MLAs).

Main demands that we put forth to elected representatives and the Minister were-

- Reverse budget cut (500 crores) in the allocation for Public Health and Family Welfare Department and demanded increase in the public health budget substantially from 12,000 Cr to 20,000 Cr
- O Start 'Free Medicines and Free Investigations scheme' in Maharashtra on the lines of Rajasthan and Delhi Government
- Enact Maharashtra Clinical Establishment Bill along with provisions for rate transparency, rate standardization, charter
 of patient's rights and grievance redressal mechanism
- Direct transfer of untied funds in the accounts of Rogi Kalyan Samiti and Village Health, Nutrition, water supply, sanitation
 Committee to avoid delay and corruption

This rally was an attempt to fortify CSOs on the issue of patient's rights, win popular support of the people, and gain entry into the political space of policy change.

The rally achieved two things. The rally gave much visibility to the issue of patient's rights and the coverage by the media was good. Additionally, we were successful in meeting face-to-face with many decision makers and pursue them to support patient's rights. Opening up the government arena was important for the success of our campaign.

On 15th December 2017, the Health Minister of the Maharashtra State announced in the Assembly that to curb excessive charging and exploitation by the private hospitals, the Clinical Establishment Act will be passed in Maharashtra too.

However, besides getting visibility to other issues and assurances from the ruling government, there was no tangible result in terms of the policy-change regarding demands other than MCEA.

Claiming space on the table- Struggle for patient's rights in the policy space:

After the announcement made by Health Minister of the Maharashtra State regarding enactment of the Clinical Establishment Act, Maharashtra Government constituted a committee chaired by Dr Mohan Jadhav, from the Directorate of Health Services, Mumbai, in January 2018, to give 'frank feedback' on the provisions in the proposed Maharashtra Clinical Establishment Bill 2014 before it gets moved to the next level.

Although this was a positive development, the process of committee formation was exclusionary and was heavily skewed in favor of the private health sector. The committee included representatives from the Indian Medical Association, Vidarbha Hospital Association, Pathology laboratories, Hinduja Hospital, Nanavati Hospital, Ruby Hospital, SRL Diagnostics, etc. This committee which predominantly represented the private sector interest was to provide 'frank feedback' on provisions mentioned in the Maharashtra Clinical Establishment Bill 2014, by 5th February 2018. JAA strongly objected to this move on the following grounds-

- Drafting Committee for the bill in 2014 included representatives from different associations of doctors in a majority. Then, why the Government felt the need to take their 'frank feedback' once again?
- Why does this committee not include a single representative from civil society organisations working on patient's rights issues?
- ⊙ Committee has one-third members from Corporate Sector! In the 12-member committee, four members are from Corporate Sector and big hospitals (Hinduja Hospital, Nanavati Hospital, Ruby Clinic, SRL Diagnostics)









It was surprising to see that no civil society organization got representation in the committee. Following stiff resistance from JAA, two JAA representatives were invited to be a part of deliberation in this committee. The committee accepted some of their suggestions regarding the patient's rights, however, their dissenting voice was largely ignored by the committee members. This was not surprising. In spite of limited progress through this committee, JAA managed to get the attention of the policymakers and the private sector alike. That paved the way for further advocacy.

- Gains made by Jan Arogya Abhiyan in Maharashtra Clinical Establishment Bill 2014 were retained. So, the provisions for charter of patient's rights, district level grievance redressal mechanism, enhanced representation to civil society organizations in the various official bodies/forums, provision of dedicated human resources for implementation of the legislation in the form of Directorate of Clinical Establishment were retained.
- Transparency in rates of the hospitals was included in the final draft. However, it will be only for the general ward in the hospitals. This is a significant exclusion, and JAA still fighting to make transparency in rates as a universal clause for hospital services.
- Provision for rate standardization, capping profitability of hospitals in medicines and consumables was included in the draft bill.

What we won, what remained undone?

Following key provisions suggested by Jan Arogya Abhiyan have not been included so far.

- o Display of charter of patient's rights and responsibilities at prominent place in the clinical establishment
- Patient's right to get itemized bill.
- Display of rates of facilities, services, packages on the website of the clinical establishment, if hospital has its website.
- o Display of information related to all registered clinical establishments including their rates on the Government website
- Compliance with self-declared rates of facilities and services by the clinical establishments; Penalty for irrational overcharging compared to declared rates and returning back 'extra charged amount' to patients if hospital found to be guilty of irrationally overcharging compared to their own declared rates.
- Penalty for denial of giving photocopy of clinical records to the concerned patient.

Although JAA intervened in the policy-making arena, success was limited. We were determined to make the government see the reason. It was a time to plan a follow-up action. We decided to protest. The place was again Nagpur, but this time during the monsoon session of the assembly. A new addition in our struggle were people who suffered because of the denial and negligence of the medical sector.

These people gave a new meaning to our struggle by sharing their stories and thereby creating a compelling case for the regulation of the private health sector, strengthening of the public health system, and the respect of the patient's rights. Ordinary people showed extraordinary courage to come all the way to Nagpur. They came with an intent to share their story.

12th July 2018- Rugna Satyagrah Patients' Campaign for (Insistence on Truth) - We want to tell our story



suylasr

"Many stories matter. Stories have been used to dispossess and to malign. But stories can also be used to empower and humanize. Stories can break the dignity of a people. But stories can also repair the broken dignity"

- Chimamanda Aichie

Three real stories mentioned at the start of this document are a testament to how badly the private sector needs regulation and underscores the need for the strengthening of the public health system. Above cases, and others that are not included in this document, needed a remedy and healing touch. Stories of individuals in these cases are lived experiences; it was a time to integrate their voices with our collective demand for better health care.

Many people who suffered at the hands of the public and the private health establishments participated in "Rugna Satyagraha" (Patient's Campaign for Insistence on Truth) on 12th July 2018, in Nagpur. They, along with JAA activists, campaigned to submit a memorandum to the Chief Minister, Health Minister, and various leaders of the opposition. Among multiple demands, central demand was to enact credible Clinical Establishment Act to regulate the private sector. Since people who suffered were physically present in the campaign, the decision-makers were forced to respond. The Health Minister, along with high-level officials met JAA delegates and promised to expedite the process of implementing CEA.

Key demands in the memorandum were:

- Improve medicine availability in the public health system, and take measures to establish medicine procurement corporations like Tamil Nadu and Rajasthan.
- Pass the Maharashtra Clinical Establishment Act, which should include patients' oriented recommendations given by JAA.
- Establish responsive grievance redressal mechanism regarding denial of mandatory free care to poor patients in the charitable trust hospitals.
- All the low income people who were forced to take treatment from the private hospitals because of the inadequacies in the public health system should get reimbursements of the money spent.
- Patient's whose testimonies are included in the memorandum should be addressed immediately, and punitive action should be initiated against the erring officials, and the public and private health institutions.
- Delegate recruitment rights to District Collectors for speedy induction of doctors into the public health system.
- Start Village Child Development Centers immediately to tackle child malnourishment problem. These centers were shut down by the current Government



News about the campaign was widely reported in the media. Detailed and continued coverage in media, reinforced our belief that testimonies of people who suffered give more teeth to advocacy.

Reimagining Change- Our Key Leanings:

- Struggle to regulate the private health sector will require a longer time horizon. The power of the private sector is enormous, and their cheerleaders- including some parliamentarians and bureaucrats, etc. are occupying key positions in the decision-making arena. We understand that this deeply entrenched power of the private sector in the policy-making spaces is hard to tackle by a single street protest or campaign activity. We will require a series of events and innovative methods to protect patient's rights and regulate the private sector.
- Private sector is more organized whereas patients and communities are not. Patients often lack agency. They are not organized like the private sector, neither they are heavily resourced like the private sector. However, campaigns can think of creating community spaces to share experiences of denial of health care, give visibility to these issues. Voting as a tactic was immensely useful because patients and people could relate to the idea of patient's rights.
- "There is no agony like bearing an untold story inside of you". People don't have cases they have stories, and they want to share it too. Our campaign gave that space to people. Individual testimonies not only give a glimpse into the widespread dissatisfaction regarding the medical practice but also reinforce collective spirit for social action. Moreover, testimonies are hard evidence. It cannot be refuted very easily.
- The middle class of the society is an important constituency in the struggle for the patient's rights. Looking at the pattern of voting during the campaign, we realise that discontent among middle class regarding the private health sector is enormous. One of the highlights of the voting campaign was the overwhelming participation of the middle-class population. The middle class doesn't just respond to public opinion; they shape it. Hence, the middle class is a vital constituency, and their significant participation in voting opened other possibilities of the campaign.
- The term "Patient's Rights" was far more effective than the abstract language of "Private Sector Regulation." In a campaign, we realized that the term patient's rights, as a unit of information and allegory, not just resonated with people but they intuitively understood what it would mean to them and their family. How we frame the message is important for the success of the campaign.
- Good Public Health System is in itself a natural regulator for the private medical sector. It would be a folly to understand the public health system and private healthcare sector as completely isolated entities in a developing country like India which is affected by Mixed Health System's Syndrome. Any advocacy for regulation of private medical sector should be accompanied with advocacy for more budget to public healthcare services, improvement in quality, transparency and accountability of public health services. Strong Public Health System is a natural regulator of the private medical sector. Weaker the Public Health System and more entrenched the private medical sector makes the task of regulation more difficult.

Conclusion

Oftentials, when private health sector regulation as an issue is discussed in policy-forums, this is framed as if politicians, corporate executives, and their interests have all the power but the rest of usthe people, don't. This is common control mythology that normalizes existing power dynamics and makes them appear unchangeable. JAA's campaign is an attempt to develop a counter-narrative to this dominant thinking and the hegemony of the private sector. In spite of significant way to go and small victories, we can definitely say, we are no longer accepting the things we can not change...we are changing the things we can not accept.



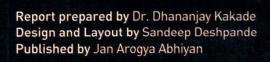
Memorandum given to Minister of Finance & Planning



Memorandum given to Member of Legislative Assembly from ruling party



Memorandum given to Ex- Deputy Chief Minister





Memorandum given to Health Minister



Memorandum given to Ex-Deputy Chief Minister



Memorandum given to Member of Legislative Assembly from opposition

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MOVING TOWARDS A CAMPAIGN ON RIGHT TO HEALTH AND HEALTH CARE - INDIAN CONTEXT

Analysis of cases related to Access to Health Care

Project Assignment Interface of Law, Health and Medicine

> Submitted by Amulya Nidhi ID No. ML&E521/2002 2002- 2004

NATIIONAL LAW SCHOOL OF INDIA UNIVERSITY BANGALORE JUNE 2004

Moving towards a campaign on Right to Health and Health Care: Indian context - Amulya Nidhi

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TABLE OF CONTENTS

Abbreviations	5
Health in todays context Conceptual framework	8
II. Right to health and health care – Conceptual framework	12
III. Legal provisions related to Right to health and health care	16
IV. Denial of Right to health careV. Ways ahead – Building a Campaign on the Right to health and health care	20
	24
VI. Conclusions and Recommendations	
References	

ABBREVIATIONS

AMS : Adivasi Mukti Sanghthan

CEDAW : Convention on the Elimination of All Forms of Racial Discrimination

CEHAT : Centre For Enquiry into Health and Allied Themes

CPA : Consumer Protection Act

EPI : Expanded programme on immunization

GOBIFFF : Growth, Oral rehydration, Breast feeding, Immunization Female literacy,

Family planning and Food supplements

ICCPR : International Covenant on Civil and Political Rights

ICESCR : International Covenant of Economic, Social and Cultural Right

IMR : Infant Mortality Rate
JSA : Jan Swasthya Abhiyan
MPW : Multi Purpose Worker

NFHS : National Family Health Survey NGO : Non-Governmental Organisations

NHP : National Health Policy

NHRC : National Human Rights Commission

PHC : Primary Health Care

PIL : Public Interest Litigation

SPHC : Selected Primary Health Care

UDHR : Universal Declaration of Human Rights

UNICEF : United Nations International Children's Emergency Fund

WHO : World Health Organisation

HEALTH IN TODAY'S CONTEXT

INTERNATIONAL SCENARIO:

In 1978, at Alma Ata the World Health Organisation (WHO) and the UNICEF presented a radical new strategy as a part of the target of achieving 'health for all by the year 2000'. Important principle of the Alma Ata declaration is that health for all can be achieved through primary health care (PHC). It says, "that primary health care is the key to attaining this target. It is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation". The central message of the PHC strategy was a call for equity and social justice.

Such a radical strategy was bound to have its opponents. Within a year of signing the declaration, an alternative approach to PHC, the selected primary health care (SPHC) was being widely disseminated. This approach argued that PHC is not cost-effective, in fact it was too expensive. A more effective method of decreasing mortality and morbidity lay in the selection and prioritisation of selected number of diseases². This approach quickly gained acceptance among donors. UNICEF introduced the growth, oral rehydration, breast feeding, immunization female literacy, family planning and food supplements (GOBIFFF). The expanded programme on immunization (EPI) was given considerable support by multi-national donors. These selective programmes are, as Rifkin and Walt have argued, a departure from the key principles of PHC³. Its approach is efficiency rather than equity; the market rather than social justice; the disease rather than social, economic and political development. The WHO's Strategy of 'Health for All for the 21st Century' is a benign neglect for those who cant afford to be part of the market⁴. For the poor, of both South and North, health for all for the 21st century will not lead to a world where health will be a fundamental human right — a state of complete physical, mental and social well-being and not just the absence of disease and infirmity.

NATIONAL CONTEXT

Health Policy

In the first two Five-year Plans following India's independence there appeared to be a commitment to address the health needs of the populations comprehensively – with preventive, promotive and curative care provided through a wide network of community based health centres, in tune with the recommendations of the Bhore Committee. But in the years that followed, the health sector was driven by technological forces and has become physician centred, reducing the pursuit of health to the provision of medical care, ignoring the broader determinants of health⁵.

Despite significant strides in eradicating communicable diseases and smallpox and in containing malaria and tuberculosis, the health status of vast majority of the people are far from satisfactory. Even though the country had aimed at attaining health for all by year 2000 it has become a distant dream even in the beginning of 21st century. The 1983 National Health Policy (NHP) was meant to arrive at an integrated, comprehensive approach towards the future development of medical education, research and health services to serve the actual health needs and priorities of the country. Critical of the curative model of

² J.A., Walsh and K.S., warren, "Selective Primary Health Care", 301 (18) New England Journal of Medicine, 967-74 (1979).

WHO "Investigating in Health Research and Development", World Health Organisation (1996).

¹ International Conference on Primary Health Care, Alma Ata, USSR, 6-12 September, (1978).

³ S.B. Rifkin and G. Walt, "Why Health improves: Defining the issues concerning Primary Health care and Selective Primary Health Care", 23(6) Social Science and Medicine (1988).

S, Saha and TKS Ravindran, "Gender gaps in Research on Health Services in India", 4 (2) Journal of Health Management, 185-214 (2002).
 Government of India, "Statement on National Health Policy", Ministry of Health and Family Welfare, New Delhi, (1982).

health care, it emphasised a primary health care approach to prevent illness and promote good health. The next decade saw the rural health infrastructure develop with a massive expansion of primary health care facilities. However, this effort was sabotaged by a combination of poor quality facilities, inadequate supplies, ineffective managerial skills, poor planning, monitoring and evaluation. The private health sector has grown phenomenally since, thanks to state subsidies in the form of medical education, soft loans to set up medical practice, etc. accounting for 70-80 percent of all primary care sought, and over 40 percent of all hospital care, in a country where over three-fourths of the population lives below subsistence level. In fact the Draft National Health Policy released by the Ministry of Health and Family Welfare in 2001 further legitimized these trends. It completely omits the very concept of comprehensive and universal health care. The Draft departs from the fundamental concept of the NHP 1983 and the Alma Ata Declaration. The draft, for all the rhetoric on community participation, is replete with "top down" prescriptions. While admitting the wastage involved in running centrally sponsored vertical programmes, it goes on to recommend that we would need to retain many of them!7 The draft legitimizes further privatization of the heath sector.

Therefore today we find that the private sector has virtual monopoly of ambulatory curative services in both rural and urban areas and over half of hospital care. The health care market is based on a supply-induced demand and leading to an increase of the cost of health services. Thus India today has a large, unregulated, poor quality, expensive and dominant private health sector, and an inadequately resourced, selectively focused and declining public health sector.

Besides not formulating people's friendly health policy, the State's insufficient commitment to provide health care for its citizens is reflected in the inadequacy of the health infrastructure, low levels of financing and also in declining support to various health care demands of the people. Under structural adjustment since 1991 there has been further compression in government spending in its efforts to bring down the fiscal deficit to the level as desired by the World Bank. This global pressure on the Indian State is evident through its policies of focusing on selective services, for instance RCH and AIDS receive overriding support over primary health care or basic referral services. Another trend that further reduces access is the increased corporate control of health care. New medical technologies have helped complete the commodification of health care.

Given the above context, it is natural that health status of the Indian population would be unsatisfactory. There is no dearth of evidence to show that India's health indicators are one of the worst in the world. India's population is characterised by high levels of morbidity especially among infants and children, women, and the elderly; and high incidence of communicable diseases associated with low levels of sanitation, public hygiene and poor quality of drinking water⁸. Infact the latest Human Development Report shows a downward trend in India's global ranking⁹. For millions of people the enjoyment of the right to health remains a distant goal.

Health Infrastructure

India has a vast health sector, which is broadly divided into the public sector, the private sector and the household. The public sector is comprised of the health care facilities set up by central and the state governments, municipal and local bodies. The private sector consists of private physicians and a range of other practitioners including those practicing non-allopathic systems of medicine, health facilities and corporate hospitals operating for profit and non-governmental organisations (NGOs) operating as non-profit enterprises. Households or self-medication provide first level care in many settings as in many places as health services are unavailable or unaffordable to a large section of the population. Various national level

⁷ Response of the National Coordination Committee of the Jan Swasthya Abhiyan to Draft National Health Policy, 2001 (unpublished).

⁸ Abusaleh Shariff, *India Human Development Report*, New Delhi: Oxford University Press for the National Council for Applied Economic Research (1999).

⁹ UNDP Human Development Report (2000).

studies have shown that people's utilisation of health care is limited by their ability to pay, as well by the

In any case today, studies on household expenditure on medical care have shown that poor people trend to seek medical care from the private sector. The irony is that this observation is being seen as a proof of their "willingness to pay" for treatment costs, while this may be more a reflection of an absence of other options than an exercise of "real choice". These observations have legitimized the introduction of "user fees" in public health facilities. We need to understand the move to phase out the state owned services in this context as a logical step towards unregulated primate monopoly in curative medical care.

As argued above, the health sector, today, faces three major challenges: adequate prevention, enhancing equity in access to health care and health status, and getting more value for money. Unfortunately there are no significant initiatives in this regard. There is no visible movement to improve implementation in public sector, or target public sector expenditure to the poor, or restructure private sector to remedy deficiencies of health care market through health insurance and appropriate regulation.

METHODOLOGY

Purpose of the research

Having stated the health scenario of our country and having been involved with various initiatives for 'right to health and health care', I saw this as an opportunity to analyse the concept of 'Right to health and health care' so as to move towards building a campaign for right to health and health care. Focus of research

The primary questions researched into, the course of the paper is:

- 1. What does right to health and health care mean?
- 2. What are the various legal provisions related to right to health and health care?
- 3. To examine how health care providers in our country are violating these various provisions.
- 4. What are the various initiatives that have taken place towards achieving right to health and health

Research methodology

This research is an analysis of secondary materials. Primary data is also used for analysis.

II. RIGHT TO HEALTH AND HEALTH CARE - CONCEPTUAL FRAMEWORK

Human rights are legally guaranteed by human rights law, protecting individuals and groups against actions that interfere with fundamental freedoms and human dignity. They exist to protect individuals from abuses of state power and obligate states to provide the conditions necessary for prosperity and well being. This does not mean that human rights apply exclusively to the relations between the state and the individuals; they, and the principles underlying them, also inform and structure relationship among individuals, particularly where there are power inequalities among those involved (eg between health care provider and patient)¹⁰.

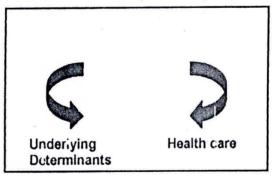
Human rights empower the poor by granting them rights that are legally guaranteed, while at the same time imposing obligations on governments and public bodies such as international organizations. Because human rights are generally legally binding, these bodies are accountable for ensuring that these entitlements cannot be reduced to mere privileges or luxuries or left to the whim of markets.

Every human being has the right to the highest attainable standard of physical and mental health (referred to as "right to health"), conducive to living a life in dignity was first reflected in the WHO constitution (1946) and then reiterated in the 1978 Declaration of Alma Ata and in the World Health Declaration adopted by the World Health Assembly in 1998. According to the General Comment 14 of the International Covenant on Economic, Social and Cultural Rights 'The right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health'11. This right is one of the fundamental human rights and is closely related to and dependent upon the realization of other human rights which are the underlying determinants of health, that is access to safe and potable water, adequate food, nutrition, housing, work and education and on provision of health care service.

The Right to health care as a component of the Right to Health

Looking at the issue of health under the equity lens, it becomes obvious that the massive burden of morbidity and mortality suffered by the deprived majority is not just an unfortunate incident. It constitutes the daily denial of a healthy life because of profound structural injustice, within and beyond the health sector. The denial needs to be addressed in a rights-based framework that has gathered momentum in the late 90's, by systematically establishing the right of every citizen to a healthy life. Right to Health is a part of the Right to Life -, the Right to Life with dignity and right to livelihood. Right to health care means having appropriate, accessible and quality health services for all people. According to WHO, to promote the right to health, action is required on two related fronts as depicted in Figure 1.

Fig 1
THE RIGHT TO HEALTH



In May 2000, the Committee on Economic, Social and Cultural Rights, which monitor the International Covenant of Economic, Social and Cultural Right, adopted a General Comment on the right to health.

National Centre for Advocacy Studies, "Right to Health", 3(5) Advocacy Internet, sept-oct (2001).

¹¹ General Comment 14, CESCR, E/C. 12/2000/4. Twenty second session Geneva, 25April - 12 May (2000).

General Comment applies to nations that have ratified ICESCR and India is one of the states to ratify it. It addresses the content of right to health and the implementation and enforcement of the right to health. According to that the following criteria was set to evaluate the right to health –

- a) Availability adequate number of functioning public health and health care facilities, goods and services.
- b) Accessibility health facilities should be accessible and affordable to everyone without any discrimination.
- c) Acceptability all health facilities should be appropriate and sensitive.
- d) Quality health facilities must be scientifically and medically appropriate and of good quality 12.

General Comment 14 reaffirms that several "core" obligations have been established in prior human rights instruments: These core obligations, as well as additional obligations are presented in Figure 2¹³.

Figure 2 GENERAL COMMENT 14 OBLIGATIONS REGARDING THE HUMAN RIGHT TO HEALTH

Core Obligations Established in Prior International Human Rights Instruments:

To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups:

To ensure access to the minimum essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone;

To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;

To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;

To ensure equitable distribution of all health facilities, goods and services;

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 all vulnerable or marginalized groups.

Obligations of Comparable Priority:

To ensure reproductive, maternal (pre-natal as well as post-natal) and child health care;

To provide immunization against the major infectious diseases occurring in the community;

To take measures to prevent, treat and control epidemic and endemic diseases;

To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them;

To provide appropriate training for health personnel, including education on health and human rights.

¹² Kinney, E.D. 2001. The International Human Right to Health: What does this mean for our Nation and World?', Indian Law Review, pp 1457-1475.

¹³ General Comment 14, CESCR, E/C. 12/2000/4. Twenty second session Geneva, 25April - 12 May (2000).

A rights-based approach to health entails recognizing the individual characteristics of the population groups concerned. In the 70s and 80s in India there was an initiative to move from health care centred health service delivery to community based health worker programmes, trying to provide affordable and rational care to the villages. The same period also saw the emergence of specific campaigns related to drug policy, hazardous contraceptives, etc. This approach received a set back at the turn of the nineties when resource commitments in the public health sector declined.

This is reflected at one level in slowing down of improvements in health outcomes and the widening rural-urban gap of these outcomes. And at another level the public health care facilities are getting incapacitated because the necessary inputs that are needed to run these facilities are not being adequately provided for. The 2002 National Health Policy unashamedly acknowledges that the public health care system is grossly short of defined requirements, functioning is far from satisfactory, that morbidity and mortality due to easily curable diseases continues to be unacceptably high, and resource allocations generally insufficient (MOHFWI4). The evidence for this is clearly brought out in the changes one sees across the 42nd and 52nd Round National Sample Surveys¹⁵, when over this decade utilisation of private health services, especially in the hospital sector, increased substantially, out-of pocket spending galloped, indebtedness due to health care affected half the users and the proportion of non-utilisation also increased.

Therefore besides having poor health indicators, India also has the dubious distinction of being among the most inequitous countries of the world, as far as health status of the poor compared to the rich is concerned. What is even more serious is the fact that these inequities, instead of decreasing over time, are increasing. Some striking facts in this regard are 16 -

Infant mortality among the economically lowest 20 percent of the population is 109, which is 2.5 times
the infant mortality rate (IMR) among the top 20 percent population of the country.

Under-five mortality among the economic bottom 20 percent of the population is 155, which is not only
unacceptably high but is also 2.8 times the rate of the top 20 percent.

Child mortality (1-5yrs age) among children from the 'Low standard of living index' group is 3.9 times
that for those from the 'High standard of living index' group according to recent NFHS data.

Tribals, who account for only 8% of India's population, bear the burden of 60 percent of malarial deaths
in the country.

Such gross inequalities are of course morally unacceptable and are a serious social and economic issue, and also exemplify the impact of globalisation-liberalisation policies in widening the gap between the rich and the poor. In addition, such a situation may also be considered a gross violation of the rights of the deprived sections of society, an invisible daily Holocaust. This becomes even more serious when viewed in the context of gross disparities in access to health care ¹⁷-

The richest quintile of the population, despite overall better health status, is six times more likely to
access hospitalisation than the poorest quintile of the population. This actually means that the poor are
unable to afford and access hospitalisation in a large proportion of illness episodes, even when it is
required

 The richest quintile accounts for 38.5 percent of inpatient days, while the poorest quintile accounts for just 6.6 percent, out of the total hospitalisation days for the population.

^{14,} Government of India, "National Health Policy 2002", Ministry of Health and Family Welfare, New Delhi, (2002).

¹⁵NSS-1987:Morbidity and Utilisation of Medical Services, 42nd Round, Report No. 384, National Sample Survey Organisation, New Delhi; and NSS-1996:Report No. 441, 52nd Round, NSSO, New Delhi; 2000

¹⁶ Abhay Shukla Creating a consensus on the Right to Health Care, Paper presented at National Meeting on Right to Health Care, Mumbai, February 14, (2002).

¹⁷ Abhey Shukla Creating a consensus on the Right to Health Care, Paper presented at National Meeting on Right to Health Care, Mumbai, February 14, (2002).

 As high of 82 percent of outpatient care is accessed from the private sector, which is met almost entirely by out-of-pocket expenses, which is again often unaffordable for the poor

About three-fourths of spending on health is made by households and only one-fourth by the
government. This often pushes the already vulnerable poor into indebtedness, and in over 40 percent of
hospitalisation episodes, the costs are met by either sale of assets or taking loans.

It is at this context the issue of 'Right to Health and Health Care' is being raised today. The next chapter would highlight how this right can be addressed.

III. LEGAL PROVISIONS RELATED TO RIGHT TO HEALTH AND HEALTH CARE

We can view the justification for this right at three levels – human rights issue, constitutional-legal and socio-economic issue.

Human rights justification

The right to health is solidly embedded in international human rights law. It is explicit in Article 25 of the Universal Declaration of Human Rights (UDHR), adopted by the United Nations (UN) General Assembly in 1948 (WHO). It is not a treaty but a statement of policy and a call to action much like the Declaration of independence. It affirmatively states a human right to health 18:

"Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including...medical care...and the right to security in the event of ...sickness, disability..."

Numerous subsequent international and regional human rights treaties have given further definition to the right to health. In the 1960's the UN sponsored the development of two international covenants that articulate the human rights recognized in the Universal Declaration of Human Rights. These two covenants are the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

The International Covenant on Economic, Social and Cultural Rights (ICESCR)-the so-called Economic Covenant-is the most important in terms of the right to health. Article 12 of ICESCR states that the right to health includes "the enjoyment of the highest attainable standard of physical and mental health¹⁹." The relevant provisions of this covenant are presented in Figure 3.

Figure 3 The International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12

- 1. The States Parties to the present Covenant recognize 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 realization of this right shall include those necessary for:
 - (a) The provision for the reduction of the stillbirth-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.

A human right to health is also recognized in numerous other international human rights authorities that establish prohibitions against government conduct that is detrimental to health. Such treaties include the International Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) of 1979, Convention on the Elimination of All Forms of Racial Discrimination, and the Convention on the Rights of the Child of 1989. Figure 4 presents the health contexts of these conventions:

18 Universal Declaration of Human Rights, Adopted by the UN General Assembly Resolution 217 A (III) of 10 December 1948.

¹⁹ International Covenant on Economic, Social and Cultural Rights, Adopted by UN General Assembly Resolution 2200 A (XXI) of 16 December (1966). Enforced on 3January 1976 in accordance with Article 27.

Figure 4

- ◆ States shall ensure to (women) access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning..... States shall eliminate discrimination against women in...... health care to ensure, on a basis of equality of men and women, access to health care services.....; ensure appropriate services in connection with pregnancy States shall ensure that [women in rural areas] have access to adequate health care facilities, including information counseling, and services in family planning........ (Convention on the Elimination of All Forms of Discrimination Against Women, Articles 10, 12 and 14)
- States undertake to eliminate racial discrimination and to guarantee the right of everyone the right of everyone, without distinction as to race, colour or national or equality before law, the right to public health, medical care, social security and social services...... (Convention on the Elimination of All Forms of Racial Discrimination, Articles 5)
- States recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illnesses and rehabilitation of health (Convention on the Rights of the Child, Articles 24²⁰)

Also of interest, is the 1993 Vienna Declaration and Programme of Action emphasizes the fundamental interrelatedness of political and civil human rights and economic social and cultural human rights. The Vienna Declaration specifically provides:

"All human rights are universal, indivisible and 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."

The Vienna Declaration has become a crucial principle in international human rights law recognizing the irreducible truth that all human rights must be recognized if specific human rights are to have concrete meaning²¹.

Reference can be made to other similar international conventions, wherein Government of India has committed itself to provide services related to right to health, for instance the Alma Ata Declaration. National Human Rights Commission (NHRC) has also concerned itself with this issue of right to health.

Constitutional and Legal justification

The issue is, how far these international obligations, agreements, treaties and covenants bind the Indian state and Nationals? Unfortunately, in the Indian Constitution, health is not a fundamental right of citizens, but has to be inferred from the broader parameters of social and economic justice. For instance, the Preamble of the Constitution of India directs the State to initiate measures aiming at improving, the health of the people. The same logic can be stretched to the Fundamental Right – Protection of Life and Personal Liberty.

Only in the Directive Principles is it categorically stated about State's responsibility to health of its citizens and regarding provision of health care. Article 39 states that

United Nations Convention on the Rights of the Child, 1989, Adopted by UN General Assembly Resolution 44/25 of 20 November (1989).
 E.D. Kinney. "The International Human Right to Health: What does this mean for our Nation and World?", Indian Law Review, 1457-1475, (2001).

"The state shall, in particular, direct its policy towards securing; that the health and strength of workers, men and women, the tender age of children be not abused and that citizens are not forced by economic necessity to enter a vocation unsuited to their age or strength".

Article 4722 of the Constitution states that

"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......"

Thus, the article 47 of the constitution under the directive principles of state policies define health both in general terms as well as and specifically in terms of health care. Conceptually, this is a great advantage, as the healthy living is not construed only to medical care but also of good nutrition and living standards. This provides a wider scope for legislating on the issue of health and health care.

Though right to health and health care has not been expressly incorporated in the Constitution as a fundamental right, but due to some pioneering and progressive judgments, right to health has acquired that status. Scope for such a kind of interpretation has created by the important judgment of the Supreme Court in the *Paschim Banga Khet Mazdoor Samiti and others V. State of West Bengal and other, 1996*, while interpreting Article 21 the Supreme Court has indisputably held that providing adequate medical facilities for the people is an essential part of the obligations undertaken by the Government in a welfare state. Similarly in the cases *Bandhua Mukti Morcha v. Union of India and others, 1982* concerning bonded labourers, the Supreme Court gave orders interpreting Article 21 as mandating the right to medical facilities for the workers²³. In another landmark judgment in 1995, the Supreme Court stated that right to health and medical aid of workers during services and thereafter, is a fundamental right²⁴. Similar judgments by Supreme Court by interpreting Article 21 has established right to treatment in emergency situation, worker's right to clean environment and health care facilities, right to privacy as a component of health care and also other aspects related to issues of quality of health care services²⁵.

Other Constitutional obligations related to health are that Public health and Sanitation is a state subject as given in the Seventh Schedule, Article 246, list II-6 of the Indian Constitution. This provision assumes importance as this means that without changing any constitutional provisions, the states can make provisions for improving public health. The 73rd and 74th Constitutional Amendments Act, 1992 provide for involvement of Panchayati Raj institutions and Nagar Palikas in all developmental programmes including Public health.

The Consumer Protection Act (CPA) addresses the aspect of medical negligence in the country. But many times CPA acts as a hindrance to provision of emergency medical care as doctors are scared that if the condition of the patient detoriates they may be charged for medical negligence.

The social and economic justification

Health as a basic human right should be viewed holistically and its positive aspect, that is well-being should be acknowledged which would lead to achievement of a socially and economically productive life. The right to equality encompasses within itself the right to a poor patient to get adequate treatment from the state irrespective of the cost.

It is now widely recognised that besides being a basic human right, provision of adequate health care to a population is one of the essential preconditions for sustained and equitable economic growth. The

²² P.M. Bakshi, 'The Constitution of India', Delhi: Universal Law Publishing Co. Pvt Ltd. (2000).

²³ A. Shukla, "The Right to Health Care Moving from Idea to Reality", Paper presented in Media Workshop on Key Issues of Health and Health Care, 21st February, Indian Social Institute, New Delhi, organised by CEHAT (2004).

 ²⁴ Centre for Social Justice "Constitutional Provisions and Supreme Court Judgments on Right to Health", Ahmedabad (unpublished).
 ²⁵ S.V. Joga Rao, "Fundamental Right to Health and Health Care", Country Report on Status of Health care, CEHAT, (unpublished).

proponents of 'economic growth above all' may do well to heed the words of the Nobel Laureate economist Amartya Sen:

'Among the different forms of intervention that can contribute to the provision of social security, the role of health care descrees forceful emphasis ... A well developed system of public health is an essential contribution to the fulfilment of social security objectives.

...we have every reason to pay full attention to the importance of human capabilities also as instruments for economic and social performance. ... Basic education, good health and other human attainments are not only directly valuable ... these capabilities can also help in generating economic success of a more standard kind ... (from India: Economic Development and Social Opportunity by Jean Dreze and Amartya Sen)

This chapter briefly dealt with relevant constitutional provisions and legal enactments regarding health. It is in this enforcement of these obligations that the Courts can play an effective role in safeguarding the rights of the citizens. Supreme Court has upheld right to health through some progressive judgments but it should not be left to the interpretation of judges only. The following chapter would highlight how right to health and health care has been systematically denied to people.

IV. DENIAL OF RIGHT TO HEALTH CARE

In this chapter I would present selected cases where people's right to health care has been violated. These cases are from Barwani and Jhabua districts of Madhya Pradesh and Thane District of Maharashtra, which were presented in a Public hearing in Sendhwa on 4th september2003 organised by Adivasi mukti Sanghatan and Mokhada on 9th January 2004 organised by Shoshit Jan Andolan. In the public hearing²⁶ the relatives or the patients themselves narrated their suffering of denial of primary health care in public health care facilities. These public hearing were organised as part of Right to health care campaign initiated by Jan Swasthya Abhiyan. These cases were collected by volunteer/staff of CEHAT, activists of Adivasi Mukti Sanghatana, Khedut Mazdoor Chetna Sanghatana/Narmada Bachao Andolan and activists associated with Shoshit Jan Andolan.

Case Study 1

Mr. N, a poor adivasi, was residing with his family of 6 members in J village of a block of Barwani district. In the night of 23rd June, 2003 his son K had a severe problem of vomiting and loose motions. Next day the Multi Purpose Worker (MPW) gave him an ORS packet. When no improvement was observed in the child's condition, it was suggested that he be taken to the nearest Primary Health Centre (PHC), where the medical officer treated him. But, after sometime bleeding started from inside the mouth and nose of the child. At another doctor's suggestion, Mr. N had to shift his child to Sendhwa PHC. Due to lack of money he had to bring the critically sick child in a brick loaded truck. The earlier PHC didn't have ambulance for this emergency situation.

In Sendhwa PHC too, he had to purchase injections and syringes worth over hundred rupees. Later when the condition became more serious, it was suggested that he take the child to Barwani district hospital. But Mr. N, a poor adivasi, did not have money for the transport and further treatment, and ultimately decided to come back to home. On the way back home his child died.

"This case study demonstrates how a PHC is not able to provide essentia" health services, not even an ambulance in an emergency condition, to save the life of an ill child. This case shows violation of Right to a set of basic health services which is guaranteed to us by Article 21 of the Indian Constitution and also Article 24 of the Convention on the Rights of the Child.

Case Study 2:

Mr. D is a 90 year old man of K village of a block in Barwani district. Sometime ago he was not being able to pass urine and was suffering from acute urinary retention. Due to this problem he was taken to Sendhwa PHC for treatment, where the doctor checked him and referred the patient to Karuna Hospital (Private) by saying that he is not able to give him treatment here. Urinary retention is an acute surgical emergency and is simply treated by catherisation, which means a tube has to be inserted to drain the urine from the urinary bladder. This simple facility should be available at the PHC level.

In this emergency condition, the family had to take the patient to Karuna Hospital where the doctor was surprised that catherisation which is easy treatment, could not be given to this old man in the PHC. Hence the person had to suffer and had to spend Rs. 1200/- on treatment, which could have been freely available.

This case shows violation of Right to emergency medical care, and right to essential drugs at an affordable cost. This case shows that these violations amount to violation of Article 21 of the Indian Constitution,

²⁶ The process of Jan Sunwai is presented in the next chapter.

Article 12 of the International Covenant on Economic, Social and Cultural Rights and also Article 25 of the Universal Declaration of Human Rights.

Case study 3

The only family planning service that is mostly provided in the PHC is tubectomy. It is generally conducted in overcrowded camps held occasionally by the government at the PHCs. The main aim of doctors and ANMs in these carnps is to fulfill the set target and therefore the operations are often done insensitively and in unhygienic conditions. No attempt is made to explain to the women what is being done to them. Often women from the interior villages are forced to walk long distances to get home the same day.

In one of these type of camps, Ms. M, a 30 year old women from K village, went to the family planning camp held at Sondhwa PHC in Sondhwa block. After her operation, which was conducted in overcrowded conditions, she returned home the same day. A week later she went to the PHC to get the stitches removed and returned home the same day. Two days later she developed severe abdominal pain and was admitted to the civil hospital in Alirajpur. Here she was diagnosed with tetanus and was also told that treatment will not be possible in that hospital and she would have to be taken elsewhere. Since the family did not have the money for further expenses they took her back home where she died three days later.

Here is a case of negligence by the government health facility and reflects the over-keenness of its personnel to fulfill their agenda and targets rather than provide quality health services. Also there is extreme insensitivity as when she was detected to have suffered from tetanus they simply referred her abdicating themselves of all moral responsibility of heath care provider.

This case shows the violation of Right to monitoring and accountability mechanisms and the Right to privacy and the provisions that was specially provided to women under various articles of CEDAW.

Case Study 4

Mr. N, age 65 years, resident of taluka Mokhada had diarrohea. On June 7, 2003 after four to five bouts of loose motions he got dizzy, broke into a cold sweat and became semi-conscious. His wife and some other villagers carried him to the Khodala PHC and the wife went to look out for the lady doctor. It was about 5.00 p.m. The wife met the doctor and told her about her husband's condition. The doctor got very irritated and told the woman that her duty hours were over and she was about to go home. She then asked her to move the patient to Mokhada Rural hospital and left the premises. The woman then went to the residences of the three resident nurses and begged them to treat her husband. They refused saying that they were not on duty and the nurse on night duty would attend to him. The nurse on night duty never turned up so once again she went to the houses of the resident nurses. Finally one nurse Ms. Z took pity and came to the PHC. She gave the patient an injection and administered a bottle of saline. The nurse told them they could not stay in the PHC as there was nobody to attend to them, and she could not stay any longer. Finally the patient was taken to a private doctor, Dr. K in Khodala. He administered another bottle of saline and asked them to go home and return the next day as there was no facility to admit him. The patient spent a total of Rs. 300 for treatment with the private doctor.

A patient with diarrhoea, requiring rehydration could not get admission in a PHC. The doctor, supposed to be on call around the clock, refused to attend to the patient and no nurse was available to attend to an admitted patient, forcing the relatives to pay for the expensive services of a private doctor. This case shows the violation of Right to emergency medical care. This case shows that besides violating Article 47 of the Constitution, it also violated provisions of the International Covenant on Economic, Social and Cultural Rights and Universal Declaration of Human Rights, which India is a signatory.

Case Study 5

Mr. M, age 44 years, resident of Taluka Mokhada, fell from a tree on 15th November 2003. He was brought to the Mokhada Rural hospital immediately. The doctor admitted him and asked the relatives of the patient to purchase two bottles of saline, which were administered to him. They then asked them to shift the patient to Nashik Civil Hospital and informed them to hire a private vehicle as no ambulance was available. The next day the patient was taken to Nashik Civil hospital where he was admitted. The doctors there advised the relatives to take him to a private hospital for a C.T. scan as the equipment in the Civil hospital was out of order. The relatives could not afford a C.T. scan so the patient was discharged after fourteen days and has now become crippled due to lack of proper treatment.

A taluka level Rural Hospital there was no ambulance available to transport such a needy patient. The Civil Hospital in a large city like Nashik could not provide the CT scan facility, resulting in a person becoming permanently disabled due to denial of hoalth care. This case shows the violation of Right to a set of basic public health services, Article 12 of the International Covenant on Economic, Social and Cultural Rights, which says that everyone has the right to the enjoyment of highest attainable standard of physical and mental health and also the interpretation of Article 21 of the Constitution as mandating the right to treatment in emergency situation.

Case Study 6

Mr. G, age 2 years, was suffering from diarrohea and vomiting. He was taken to the Tokavda PHC by his mother on the morning of December 25, 2003. The doctor did not examine the child and gave only a packet of ORS. A couple of hours later the mother informed the doctor that the child was running temperature. The doctor did not examine the child but wrote out a prescription for medicine, injection and disposable syringe, all to be purchased from outside. The child was administered the medicines purchased from the private medical store and sent home. The next day the mother returned with the child and she was once again asked to purchase medicines from outside. On the third day the mother did not return with the child as she had no more money to purchase medicines.

Adequate treatment for diarrhoea, one the simplest and commonest illnesses, could not be given by the PHC. This case shows the violation of Right to essential drugs at an affordable cost, which is guaranteed to us by Article 21 of the Indian Constitution and also Article 24 of the Convention on the Rights of the Child.

Case Study 7

Mr. J, age 62 years, resident of Dahanu taluka, was suffering from continuous cough and breathlessness for some time. He approached the Multi Purpose Worker (MPW) of his village working through Kasa PHC for help. The MPW did not give him any assistance so he came to the Cottage Hospital in Dahanu where an X-ray was taken, they examined his blood and sputum and directed him to go to the Kasa PHC to get his treatment for T.B. under the DOTS programme. He was told that the MPW would come to his house and give him his tablets daily, which he was supposed to consume in the presence of the MPW. After a few visits from the MPW, he went on leave for 15 days and the treatment stopped. The patient went to the MPW's house to ask for the tablets but he refused to give them to him and said that he would personally administer them to him at his house. After repeated requests to the MPW, the patient complained to the doctor about the abrupt stoppage of his treatment. The MPW made only one visit gave him tablets for a few days after which the treatment was stopped till today.

Regular treatment for a case of tuberculosis, the core activity of the National TB Control Programme, was denied despite his taking repeated initiative to obtain treatment and the patient being enrolled under the much-publicised 'DOTS' programme. This case shows the violation of Right to a set of basic public health services. This is a violation of the International Covenant on Economic, Social and Cultural Rights and also the provisions guaranteed by the constitution.

Case Study 8

Ms. U, age 12 years, resident of Jawhar taluka went to school on 27th November 2003 as usual, after an early lunch at about 10.00 a.m. She vomited three times in school and then came home. She continued vomiting a number of times. At about 7.00 p.m. when her parents returned from work they rushed her to the Jawhar Cottage Hospital. She was admitted in the hospital, given one injection and some tablets but her vomiting did not stop. Her father requested the nurse on duty to attend to her but she did not pay any heed instead she scolded the parents, saying that the girl was dirtying the hospital. The parents were asked to give her glucose water orally which they administered the whole night. The girl could not sleep, she had high fever and she was crying incessantly, however no medical staff came to see her despite several requests. At about 6.00 a.m. the next day the girl's stomach become distended. Even then no medical staff on duty attended the patient. At 11.00 a.m. the doctor came on his routine round, examined her pulse and moved on. The parents requested the doctor to give the child intravenous saline, since she was not able to swallow the glucose water but he did not pay any heed. At about 12 noon the child became unconscious. The father rushed to the doctor who was on duty at lawhar cottage hospital, informed him. The doctor asked him to bring the patient to his chamber. By the time they brought the patient to the chamber, she had expired.

While in the Cottage hospital, the child was in severe distress for more than 12 hours, but was not given adequate attention required to diagnose or treat the underlying problem. The child died, and adequate medical attention not being given in time was a likely contributory cause. This case shows the violation of Right to a set of basic public health services. This is a violation of the International Covenant on Economic, Social and Cultural Rights, the Right to life, guaranteed by the constitution and the right of the child recongnised by the Convention on the Rights of the Child.

The above cases show that the existing situation is very dismal and the changing political economy does not show too much promise of change for the betterment of health, unless of course there is a radical transformation in the political commitment. For this to happen the support of civil society pressures and demands for a transformation of the healthcare and rehabilitation dispensation will be needed. We need to move towards the objective of establishing health care a Fundamental Right in the Indian Constitution. This would be a prolonged and challenging process, and would involve political mobilization and widespread public awareness besides other things. The time has come to begin asking as to how the human rights related commitments and concerns will be translated into action in a realistic, time bound and accountable framework. The following chapter would present the efforts undertaken so far in this direction.

V. WAYS AHEAD- BUILDING A CAMPAIGN ON THE RIGHT TO HEALTH AND HEALTH CARE

Right to health and healthcare is a fundamental social and economic right recognised by the International Covenant. But such a demand is not on the political agenda in India. This massive health care deprivation amidst potentially adequate health care resources needs to be addressed by establishing the right to every citizen to basic health care, accompanied by operationalising a system, which would ensure universal access to health care. The first step towards this direction was taken in the International Conference on Primary Health Care, meeting in Alma Ata in 1978. The Conference reaffirmed that health is a fundamental human right and that the attainment of the highest possible level of health is a most important worldwide social goal²⁷. It says that governments have a responsibility for the health of their people, which can be fulfilled only by the provision of adequate social measures.

For building an effective campaign for right to health the central task must necessarily be the task of mobilizing those who are personally facing the brunt of the anti-people policies. Any movement that is not based on the mobilization of this section is seriously limited. Though the slogan is 'People's health in People's hand', it is yet to be placed in people's hand because most organisations and networks currently focusing on right to health come from middle class backgrounds. Though even with this limitation certain demands like increase in budgetary allocation and expansion of public health services form a ground for action – but they are not adequate to form a movement.

For mobilizing this section, two approaches are useful. One is the articulation of comprehensive radical critiques, if possible with alternatives, for making out the correct political position. Another approach is to engage in lobbying and advocacy for policy changes and shaping of a public opinion. One way to generate a public debate is to take the formal judicial route, filing of Public Interest Litigation (PIL), which would draw media attention and would put pressure on the political sphere. This could lead to short term gains and this can help in sustaining mass action. But to build a larger public campaign for the 'right to health and health care' – a nation wide initiative Jan Swasthya Abhiyan (People's Health Movement – India) was initiated. Jan Swasthya Abhiyan is a campaign platform that has emerged from the People's Health Assembly process in India in 2000. It forms the Indian regional circle of the global People's Health Movement, and is a coalition of 20 National networks and several hundred organisations from all over the country working in the area of health, people's science, women's issues and development.

Jan Swasthya Abhiyan (JSA) in India has voiced a demand to make health care a right, but this requires a widespread awareness campaign and participation of many more civil society groups. This chapter would describe the various initiatives that are undertaken in the country by JSA in the direction of making health care a right.

In India to achieve right to health and health care two parallel process is needed, firstly by demanding from the Government, amendments in law and secondly by building pressure from people. As at present asking right from the formal judiciary is a long way process and it is expensive for a common man to fight with the system individually, therefore a parallel Judicial System was initiated, which is accessible and affordable to a layperson. It was known as people court. In ancient time also in villages there was a system of panch system, which solved day-to-day crime and conflicts in villages. Still in some parts of Rural India this system is functioning.

²⁷ International Conference on Primary Health Care, Alma Ata, USSR, 6-12 September, (1978).

Public hearing as a means for creating public discourse and people's mobilization-

In India, Jun sunwai as an innovative advocacy strategy was initiated by Mazdoor Kisan Shakti Sanghatana (MKSS), Rajasthan. It was initiated as part of Right to information campaign. After this in several parts of country Public hearing was organised on different social issues.

Jan Swasthya Abhiyan has emerged as a premier national level platform in India with a clear Rights-based approach to health. State and national level activities have included facilitation of 'People's Health Enquiries' in over 200 districts all over the country. In continuation with its pursuance of health rights, JSA organised Public hearings (Jan Sunwai) in various parts of the country. Here I am going to present the process of conducting Public Hearings.

Meaning of Jan Sunwai-

"Jan Sunwai is a process in which any issues related to social sector is addressed to a panel of experts from related field". In past few years Jan Sunwai (Public hearing)- as a model has become very popular in which experts from related field act as a judge and activist as a lawyer and government representative as a third party. In public hearing public officials and representative are invited to defend themselves in these hearings. This strategy encourages people to speak out fearlessly and give evidence against the misdeeds of the administration. Like in court, common people are allowed to listen to the judgments, in the same way the Public hearings is not limited only to the people actually suffered, but lawyers, intellectuals, academicians, and journalists can also be a part of the process. The judge or panel gives recommendations after listening to people's voices for immediate action so as to make relevant changes in the policy. In public hearing villagers/ common people are informed in advance about place, date and others details to be discussed. A large number of people from all walks of life participate in the hearings.

The strength of public hearing is it is being organised in local language. This encourages the poor, who are otherwise unheard of to express their negative encounters with the government system. Public hearing was not only effective as an advocacy strategy, but as a means to give the poor an opportunity to woice their dissent. It helped to increased the strength and bargaining power of people in relation to state machinery.

The well planned public hearing not only serve as a means to create mass mobilization and grassroots mobilization, but also created a lot of news value in the media. So public hearing had multiple strategic functions. Here I would present few instances of Jan Sunwai held in the country in the last one year on the issue of health care.

Regional level - Jan Sunwai - Sendhwa, Madhya Pradesh

Jan Swasthya samiti, Sendhwa, Madhya pradesh had organised a public hearing, which was hosted by Adivasi mukti Sanghatana, Sendhwa on the issue of peoples right to health on 4th September 2003. The idea of organising a Jan Sunwai was initiated in a meeting of Adivasi Mukti Sangathana at Niwali in July 2003. The process details of this important step forward in the health movement in Western Madhya Pradesh (MP) are as follows.

Organisational groundwork: In this process at first village meetings were held and specific cases of denial of health services, which led to either loss of life or endangered life were documented. Activists of POs, Volunteer MSW fieldwork students and staff associated with CEHAT and Ashagram, documented these cases. Simultaneously a meeting was organised in the month of August in Sendhwa by the Jan Swasthya Samiti, Sendhwa to discuss the present situation of public health services after 25 years of Alma Ata Declaration. In that meeting it was felt that these findings should be discussed with the people to make a wider impact.

Documenting situation of staff, services and infrastructure in PHCs, CHCs and District hospitals. In order to strengthen the advocacy to right to health care campaign, a survey was conducted in Badwani and Jhabua district by Jan Swasthya Samiti to document the situation of public health services in these areas. Here based on the checklist information was collected through observation and discussion with PHC/CHC staff. Information was collected from a total of 31 PHCs, 5 CHCs and 1 District hospital. Secondary data available at District Health Departments were collected to supplement the field level data. Based on this information a report was prepared which highlights the stated and actual provision of public health services in the districts.

Mobilization of People: In this process, activists of Adivasi Mukti Sanghthan (AMS) did mobilisation at village level. Besides other NGO/Peoples Organisation like Khedut Mazdoor Chetna Sangath/Narmada Bachao andolan also mobilised people from Jhabua district to participate in Jan Sunwai. Almost all active groups at the area participated in this process. Keeping in view to address this issue to middle class people, doctors, media, press, teachers, lectures were also invited and were convinced by JSS people to participate in the public hearing.

The event - Jan Sunwai: This entire process culminated in the Jan Sunwai organised on 4th September 2003 at Sendhwa in which around 200 people participated. It was organised by Jan Swasthya Samiti, Sendhwa and hosted by Adivasi Mukti Sangathana, Sendhwa. A panel consisting of Dr. Anant Phadke, health activist from Pune, Dr. T.Sundararaman, Health Advisor to Chattisgarh government, Dr. Rahul Sharma, Convenor of BGVS, Gwalior were present for the Jan Sunwai. The District Administration and Health dept were also invited for this public hearing, but they did not come for the hearing. Representatives of 9 blocks from Barwani and Jhabua districts presented their situation of public health system failure of the area. The people who faced denial of health care presented several cases. The panel was shocked to find that appropriate treatment is not given even in simple cases of diarrhoea and no treatment is available in some areas for snakebite and dog-bite. Their report says "Such gross deficiencies are a matter of shame when we enter the 21st Century". Based on that the panel suggested some recommendations and expressed their comment / opinion about the icsue. They recommended, "The CMHO needs to seriously take note of these gross deficiencies and take up remedial measures". As follow-up this report, the recommendations of the panel were submitted to District Administration & Health Department.

Subsequently it has now been decided by Jan Swasthya Abhiyan, MP that such type of Jan Sunwais would be held in different areas of the state. Like Madhya Pradesh in other states also public hearing were organised as part of Jan Swasthya Abhiyan.

National Consultation on Health Care as Human right

As a part of the campaign, on the 5th -6th sep 03, a national workshop and national public hearing of the denial of health care were held in Mumbai, the latter in the presence of the chairperson of the National Human Rights Commission (NHRC). It was attended by over 250 delegates from 16 states, dedicated to a broad spectrum of health and right based movements, including rights for women, children, people affected by HIV, displaced people, people in areas of conflicts, workers in the unorganized sector, as well as number of academicians, policy analyst and other interested citizens.

The workshop included a series of presentation, which provided the background to the issue of health care as a right, and looked at key elements of health care for groups most vulnerable to the violation of health care as a human right.

In the Consultation, Justice Anand, Chairperson of NHRC mentioned in his inaugural speech that the Supreme Court has taken a view that health care is a fundamental right. At the end of his speech he stated

his clear position that "Obligation of the state to take care of primary health is paramount, total and absolute. The state cannot avoid its constitutional obligation on account of financial constraints"28.

Other Strategies:

Besides building a public opinion through the above strategy, the other approach adopted is *initiating a dialogue with a wide variety of professional associations* like Indian Medical Associations, Medical Council of India, universities and academic research institutions and networks. This is necessary to build up an ethos of support to the campaign and would also help to counter the potential opposition of the medical industry or those who see a threat in this campaign.

The other step that is adopted is to try and evolve and integrate other health care systems and traditions would greatly enhance the demand and support base.

Jan Swasthya Abhiyan also organised a 'Public Dialogue with political parties on Health Issues' on 12th March 2004 in Delhi before the General Elections 2004. Around 300 JSA associated persons attended this public dialogue. This event involved representatives from different political parties, representatives from the media both print and electronic, expert panelists and speakers, and JSA related health activists from a dozen states. Members of some political parties also promised that they would take up issues related to health in their campaign and also in the assembly.

Besides these above mentioned national level initiatives, various state units of the JSA are also involved in state level campaigns to make right to health a reality.

The concluding chapter would focus on the issues that needs to be addressed further and strategies that need to be adopted to make "Right to Health and Health Care" a reality.

²⁸ Jan Swasthay Abhiyan, "Report of the National Workshop on Right to Health Care and National Consultation on Health Care as Human Right", 5-6th September, organised by CEHAT, (2003).

CONCLUSIONS AND RECOMMENDATIONS VI.

Like all rights, the right to health care could not be realized with judicial intervention alone, but require tremendous action by civil society. The law was only a part of the social framework with which the right to health care could be realized. The other integral part is civil society, which now needs to be strengthened through education, and a consciousness of the value of human life. The last few years has already demonstrated the tremendous power of the civil society in trying to achieve health care rights. The right to healthcare campaign is trying to bring into light the readiness at the community members to contribute towards demanding health care as their fundamental rights. This needs to be strengthened further.

After independence the state gave emphasis on enactment of new laws, modification of the colonial law and the judiciary developed case laws to consolidate people's entitlement of health care and to an extent, the rights. This development took place on the basis of numerous recommendations made by various committees like the Bhore Committee(1946) and Mudaliar committee(1961). The Bhore Committee recommended formulation of a Public Health Act, which was subsequently tried by Mudaliar committee to formulate such an act. The Mudaliar committee drafted a Model Public Health Act, which was a very comprehensive document²⁹. This draft Act aimed at being the legislative counterpart to implement fully the recommendations made by the Bhore Committee and Environmental Hygiene Committee reports and has envisaged a comprehensive and integrated health service covering all the essential fields. The Act therefore laid down statutory obligations on the State to ensure the fulfillment of the objective30. The subsequent committees failed to take their recommendations to logical conclusions. Recently the Bajaj Committee(1996) after relooking at the act has also recommended uniform adoption of Public health act. This needs to be implemented soon.

The initiative to bring healthcare on the political agenda will have to be a multi-pronged one and fought on different levels. The idea here is not to develop a plan of action but to indicate the various steps and involvements which will be needed to build a consensus and struggle for right to healthcare. To establish right to health and healthcare with the above scenario certain essential steps will be necessary, which are listed below:

- Implementation of different provision already given though different international treaty. Pressurizing international bodies like WHO, Committee of ESCR, UNCHR, as well as national bodies like NHRC, NCW to do effective monitoring of India's state obligations and demand accountability.
- Lobbying with parliamentarians to demand justifiability of directive principles. The directive principles gives full scope to the parliament to make right to health care a fundamental right. Filing public interest litigation (PIL) on right to healthcare to create a basis for constitutional amendment.
- Besides, in the absence of a will to make it a fundamental right, there is also scope for enacting a simple but comprehensive legislation for making right to health care an effective practical reality. Implementation of Model Public Health Act (if necessary with some modifications) in all states31. If the public health system fails to deliver basic health services, it should be treated as a legal offence, remedy for which can be sought in the courts of law.
- To establish a district and State level systems for People's monitoring and accountability mechanism to oversee the implementation of the various provisions.
- Generating a political commitment through consensus building on right to health care in civil society.
- Development of a strategy for pooling all financial resources deployed in the health sector

²⁹ Amar Jesani, "Right to Health Care: Entitlement and Law", Laws and Health Care Providers, CEHAT, Mumbai (1996).

Mudaliar Committee, "Appendix B – 38, Salient features of the Draft Model Public Health Act", Report of the health Survey and Planning

Committee, Vol 2, Government of India, Ministry of Health and Family Welfare, (1961).

This Act after modification was circulated to all states for its implementation in 1987. It was to be examined by all State health authorities and local health authorities to suit local and national needs.

- The medical councils must be made accountable to assure that only licensed doctors are practicing
 what they are trained for. Further continuing medical education must be implemented strictly by the
 various medical councils and licenses should not be renewed (as per existing law) if the required
 hours and certification is not accomplished.
- Strictly regulate the private health sector as per existing laws, but also an effort to make changes in these laws to make them more effective. This will contribute towards improvement of quality of care in the private sector as well as create some accountability.

The agenda for health reform is long, far-reaching and tortuous, arguing for rethink on the role of public health sector and for restructuring of the private sector. To conclude, it is evident that the neglect of the public health system is an issue larger than government policy making. The latter is the function of the overall political economy. Under capitalism only a well-developed welfare state can meet the basic needs of its population. Given the backwardness of India the demand of public resources for the productive sectors of the economy (which directly benefit capital accumulation) is more urgent (from the business perspective) than the social sectors, hence the latter get only a residual attention by the state. The policy route to comprehensive and universal healthcare has failed miserably. It is now time to change gears towards a rights-based approach. The opportunity exists in the form of constitutional provisions and discourse, international laws to which India is a party, and the potential of mobilizing civil society and creating a sociopolitical consensus on right to health care. There are a lot of small efforts towards this end all over the country. Synergies have to be created for these efforts to multiply so that people of India can enjoy right to health and healthcare. While the course and outcome of these efforts would depend on the much larger political situation, the following slogan should continue till we achieve our goal of a more humane society.

Health for All - Now!

The Right to Health is a basic human right!

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