Report of the

National Workshop on Right to Health Care: September 5, 2003
&
National Consultation on Health Care as Human Right: September 6, 2003

(Organised by Jan Swasthya Abhiyan)

(Report prepared and published by CEHAT for Jan Swasthya Abhiyan)

Jan Swasthya Abhiyan

Cehat

Report of the

National Workshop on Right to Health Care: September 5, 2003

&

National Consultation on Health Care as Human Right: September 6, 2003

(Organised by Jan Swasthya Abhiyan)

(Report prepared and published by CEHAT for Jan Swasthya Abhiyan)

CENTRE FOR ENQUIRY INTO HEALTH AND ALLIED THEMES

Contents

Preface

The 'Right to Healthcare' has emerged as a major area of work within CEHAT. At the same time the Jan Swasthya Abhiyan, the Indian chapter of the People's Health Movement, has taken up right to healthcare as its main campaign focus since last year. CEHAT and JSA have been partners in a number of initiatives linked to this and other allied issues over the last few years.

While there is no direct constitutional mandate in India on right to healthcare, the judiciary has often used the provisions in the directive principles of the Indian Constitution in conjunction with Right to Life enshrined in the chapter of fundamental rights to deliver justice in cases where health of citizens has been jeopardized. But decisions on a few such cases cannot become the basis for a justifiable right to health and healthcare. Thus the need to work towards an independent right to health and healthcare has become apparent.

Over the last one-year we have begun a process in collaboration with JSA and other organisations to consolidate this effort towards realizing this right. As part of this process we felt the need to involve the National Human Rights Commission to gain support for violations of health rights, which were taking place in different parts of the country. We are grateful to the NHRC for participating in this process and agreeing to take the process forward by holding regional consultations to document cases of denial of healthcare.

To create a basis for the above partnership, CEHAT and JSA facilitated a countrywide process to document cases of denial of healthcare. These cases were compiled with the help of JSA constituents and other support groups across the country. Over 250 activists and representatives of people's oPrefaceanizations and other civil society groups were brought together in Mumbai on September 5th and 6th 2003 in a National Workshop and Consultation on healthcare as a human right. This workshop and national consultation was organised with the help of financial support from the Institutional support programme of Cehat funded by Novib (Netherlands). While the workshop provided an opportunity for the participants to get exposed to the various dimensions of healthcare as a human right, the consultation with the Chairperson of the NHRC, Justice Dr. A. S. Anand, was an opportunity to show how violations occur and how people are denied healthcare. We would like to thank Justice Anand for a patient hearing and for lending support of the NHRC towards this cause. Also we would like to thank the members of various JSA organisations for their enthusiastic participation in this workshop. We express our gratitude towards the contribution of all the facilitators as well as all those who made thought- provoking presentations in the parallel workshops.

This is only the first step. The journey towards realizing right to health and healthcare is going to be difficult but if the enthusiasm expressed in the above event continues and all such energies are brought together the struggle will definitely bear fruits in the not too distant future.

Ravi Duggal

Coordinator CEHAT

12th January 2004

Published in January 2004

By Centre for Enquiry into Health and Allied Themes

Pune

Also copies Available at:

Mumbai Office:

Survey no. 2804 and 2805,
Aram Society Road,
Vakola, Santacruz (East),
Mumbai - 400 055, India
Tel: (91) (022) 26147727, 26132027
Fax: (91) (022) 26132039
Email: cehat@vsnl.com
Website: www.cehat.org

Pune Office:

Flat No. 3 & 4, Aman-E Terrace Society,
Plot No. 140, Dahanukar Colony,
Kothrud, Pune - 411 029, India
Tel. (91) (020) - 25452325
Phone Fax - 25451413
Email: cehatpun@vsnl.com

Printed at: Mandar Traders, Pune- 11

Introduction

Jan Swasthya Abhiyan (JSA) (translates from Hindi as People's Health Movement) has emerged from the People's Health Assembly in India. It is a coalition of 18 national networks, and more than 1,000 organizations from all over the country working in the field of health, science, women's issues and development. The inception of JSA took place during the National Health Assembly in Kolkata on the 30th of November and 1st of December 2000.

The international **People's Health Movement, which has emerged from the People's Health Assembly 2000,** is an unprecedented global process, the goal of which is to establish health and equitable development as top priorities in local, national, and international policy frameworks. Primary health care is the strategy for achieving these priorities. The Movement aims to draw upon and support people's movements in their struggles to build long-term and sustainable solutions to health problems. The People's Health Movement is a unique grassroots-to-global movement for *'Health for All--Now!'*-a campaign for better health. This innovative campaign has been active since July 1999 to enquire into the current state of health services and to demand better health care.

Since early 2000, the activities of JSA in India are carried out at the local, state and national levels. At the local level, activities include raising mass awareness on the right to health care through meetings, street-plays, posters, booklets and pamphlets, monitoring of local health centres and conducting local level health surveys and organizing block-level and district-level enquiries and conventions. State and national-level activities include meetings and workshops, advocacy for strengthening the public health system, advocating regulation of the private health sector, critiquing the National Health Policy and advocating changes, and building a national campaign on the Right to Health Care. All this is carried out by the over 1,000 organizations associated across the length and breadth of India in 18 states. The national coordination committee is constituted of the 18 national network organizations.

On the 5th and 6th of September 2003, a national workshop and a national public hearing on the denial of health care was organized by JSA, and hosted by CEHAT in Mumbai. The public hearing was in the presence of Justice Anand, Chairperson of the National Human Rights Commission. It was attended by over 250 delegates from 16 states, dedicated to a broad spectrum of health and rights based movements, including rights for women, children, people affected by HIV, displaced people, people in areas of conflict, workers in the unorganized sector, as well as a number of academicians, policy analysts and other interested citizens.

The workshop included a series of presentations, which provided the background to the issue of health care as a human right, as well as looked at key elements of health care for most vulnerable groups, such as women, children, adivasis, displaced people, communities under conflict, people affected by HIV, etc.

Milestones Along the Way to Right to Health Care

The Right to Health Care campaign in India has emerged through a series of steps during the last one-and-a-half years. Various milestones, which have framed the basis for development of the campaign, have been as follows:

(a) Fostering Partnerships Towards Right to Comprehensive Health Care on 14th February 2002 at Mumbai:

A national workshop organized by CEHAT, the National Centre for Advocacy Studies (NCAS), and the Global Health Council (GHC) brought together numerous like-minded people with the goal of promoting and strengthening alliances to advocate for the right to comprehensive health care. The discussion included a dialogue on the feasibility of organizing a conference revolving around the central theme of the right to health care. The participants broke up in small groups to brainstorm on a number of themes, including the identification of stakeholders, the definition of actions at various levels, strategies for adding health care to the political agenda. The JSA was identified as one of the key stakeholders. The idea of a conference was welcomed by the participants who suggested the formation of a core group to initiate planning, and steer the progress.

(b) Seminar on Right to Health Care: Moving from Idea to Reality, on 3rd and 4th of January 2003 at the Asian Social Forum in Hyderabad:

As a follow up of the workshop organised in February 2003, a two-day seminar was organized by CEHAT, NCAS and GHC under the aegis of the JSA on 3rd and 4th January 2003 at the Asian Social Forum in Hyderabad. This seminar was organized under the broad theme of Social Infrastructure, Planning and Cooperation. Over 150 people from all over the country attended this seminar. The aim of the seminar was to analyze and discuss issues and strategies related to establishing the Right to Health Care in the Indian context. The underlying basis of the seminar was that access to quality health care is an essential human need, a right of citizenship, and a public good, but also a pre-requisite to good health. It was felt that it was necessary to put the Right to Health Care on the political agenda and have further discussions in JSA for a campaign to start materializing.

(c) JSA National Working Group Discussions in April 2003 in Delhi and July 2003 in Bangalore:

Certain clarity about the concept of right to health and health care emerged from the Asian Social Forum (ASF) workshop. In this context during the National Working Group (NWG) meeting held in Delhi in April 2003 it was decided to take up 'Right to Health Care' as a campaign issue in the coming months. The various activities to be undertaken as a part of this campaign included the release of a national report on "State of Health Care in India--25 years after the Health For All Declaration," followed by campaigns and mobilisation on the issue. These activities would lead up to JSA's participation in the World Social Forum. Concrete campaign strategies were further discussed during the JSA-NWG meeting in Bangalore in July 2003. The documentation of denial of health care by JSA state units was seen as a vital activity towards the campaign as well as towards legal intervention. The report and the case studies would be submitted to the National Human Rights Commission. The planning of a national workshop and public consultation on the Right to Health Care also took place at this meeting. JSA representatives also agreed on the need for organising a national-level convention on the Right to Health Care to bring together political leaders, prominent social figures, health academics, etc., to bind together a commitment from a number of social streams.

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

(e) Interaction with the National Human Rights Commission:
During this process representatives of the JSA also interacted with members of the National Human Rights Commission (NHRC), particularly the Chairperson, Justice Anand, and the convener of the Health Committee, Dr Srinath Reddy, to keep them abreast of the developments, and to explore channels of involving NHRC in facilitating the campaign. Based on this interaction, Justice Anand was invited to inaugurate the National Public Consultation on 6th September 2003. It was felt that the active involvement of the NHRC would add to the strength and legitimacy of the process.

On the 5th and 6th of September 2003, a national workshop and a national public hearing of the denial of health care were held in Mumbai, the latter in the presence of the Chairperson of the NHRC. It was attended by over 250 delegates from 16 states, dedicated to a broad spectrum of health- and rights-based movements, including rights for women, children, people affected by HIV, displaced people, people in areas of conflict, workers in the unorganized sector, as well as a number of academicians, policy analysts and other interested citizens.

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

The national consultation of health care as a human right provided a glimpse, albeit heart rending, of the challenges faced in establishing a health care system that would guarantee everybody access to a reasonable standard of care, and ensure accountability from those who provide it.

National Workshop on Right to Health Care
September 5, 2003

To the casual passer-by, the calm and peaceful surroundings of the Retreat House in Mumbai would have given no indication of the buzz of activity inside! As one approached the house, noting the play of sunlight and shadows of overhead leaves on the footpath, one would expect the imposing silence of a library…

The corridors were alive with hectic activity as activists put up posters and spread out publications for others to browse through. As participants milled around the registration table, old friends caught up with each other, while new friends were introduced. People browsed through the agendas and decided which of the parallel sessions to attend, since they all looked so interesting! There were over 250 participants from 16 states, more than half being from Maharashtra. Health activists, social workers, academicians, policy analysts…people from a diverse range of social streams had come together to brainstorm, debate, and collaborate on the issue of the Right to Health Care and its various dimensions.

The overall nature of the programme was such that on the first day there were deliberations on various aspects of the Right to Health Care and what should be the content of this right. The 5th of September was a day of enlightening presentations and intense discussions.

Giving an introduction to the participants, Abhay Shukla (associated with CEHAT, and working with primary health care) presented a brief overview of the programme and the issue of Right to Health Care.

After that the participants were divided into two groups for the parallel sessions on Right to Essential Drugs and Right to Health Care in situations of conflict and displacement. The next two parallel sessions were on the Right to Basic Health Services and Women's Right to Health Care. In the post-lunch period, there were parallel sessions on the Right to Health Care for unorganized workers and the urban poor, and the Right to Health Care for HIV/AIDS affected persons. Socially sensitive experts in the relevant fields moderated all these parallel sessions.

After these sessions there were short 10-minute plenary presentations on the following topics:

- Health rights in context of the private medical sector
- Right to mental health care
- Public health sector employees and the Right to Health Care
- Children's Right to Health Care

After that the participants were split into five groups, which were based on the states from which the participants came. These groups discussed the various cases of denial, which were then collected. In each group there was one medical person to facilitate the discussion. The nature of denial and its consequence were discussed in these sessions. A total of 69 cases have been documented till now. Out of these 69 cases, six cases were selected to be presented to the Chairman of the NHRC the next day.

Overview of the Issue of Right to Health Care--Abhay Shukla

In the current era of globalisation, liberalisation and privatisation, there is a growing trend of the government's withdrawal from the public health sector and the unregulated growth of the private sector. In this situation, asserting the Right to Health and Health Care should be a people's response to neo-liberal health policies. Asserting our 'Right to Health', including the *Right to Determinants of Health* (such as drinking water, nutrition, and housing) and *Right to Health Care,* should be our overall approach. Campaigning for the Right to Health Care would be an important strategy as part of this approach.

There are a number of international covenants and conventions which endorse that health is a basic human right, and among them the International Covenant on Economic, Social and Cultural Rights (ICESCR) has defined and elucidated the Right to Health in considerable depth by means of its General Comment 14 (2000).

The Indian Constitution states:
"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 ..."
(Indian Constitution - Directive Principles, Article 47)

According to a prominent Supreme Court judgement:
"Providing adequate medical facilities for the people is an essential part of the obligations undertaken by the Government ... Failure on the part of a Government hospital to provide timely medical treatment to a person in need of such treatment results in a violation of his right to life guaranteed under Article 21."
(Paschim Banga Khet Mazdoor Samiti and others vs State of West Bengal, 1996)

Abhay Shukla defined the core content of the Right to Health Care in the first phase (to be achieved in the short to medium term) as the following:

- **Right to a set of basic public health services**
  - ⇒ Adequate physical infrastructure at various levels
  - ⇒ Adequate skilled human power in all health facilities
  - ⇒ Availability of the complete range of specific services appropriate to the level
  - ⇒ Availability of all basic medications and supplies
- **Right to emergency medical care, and care based on minimum standards from private medical services**
- **Right to essential drugs at an affordable cost, consisting of two components**:
  - ⇒ Availability of certain basic medications free of cost through the public health system
  - ⇒ A National Essential Drug Policy ensuring the production and availability of an entire range of essential drugs at affordable prices
- **Right to patient information and redressal**
- **Right to monitoring and accountability mechanisms**

The core elements to realise this goal are:

- ⇒ Strengthening and reorienting the health system and establishing its accountability
- ⇒ Enacting constitutional and legal entitlements
- ⇒ Introducing effective monitoring mechanisms at all levels
- ⇒ Generating public awareness and organising the public to demand health care as a right.

The presentation provided the foundation for understanding the issue of Right to Health Care, which was then discussed intensively in the following parallel sessions.

Summaries of the Parallel Sessions

1) Right to essential drugs:

Key issues related to Right to essential drugs:

- India has the capacity to produce enough drugs to meet domestic requirements
- Dietary supplements, cosmetic medicines and other non essential drugs and irrational combinations are a drain of national wealth
- Hazardous contraceptives opposed by women's health groups may find their way into National health programs
- Spurious drugs on the market pose a threat
- The WHO has produced a list of over 300 essential drugs, which should be the basis for drug policy.

Anant Phadke (associated with CEHAT, working on primary health care and drugs) who chaired the session started by saying that although the national-level networks, active since 1980, had succeeded in banning 68 categories of irrational drugs, there was at present a new growth of irrational drugs in the market. There was also a growing concern that a number of hazardous contraceptives opposed by women's organizations might find their way into the national health programmes. He urged the JSA to provide a platform for taking the issue forward.

Amitava Guha (associated with FMRAI, working on the issue of rational use of drugs) who facilitated the session, voiced concerns regarding the growth of irrational drug usage. He cited a number of examples, like dietary supplements, and said that this was a waste of national wealth. Research resources were being poured into developing drugs and vaccines for a few elite diseases, while diseases like tuberculosis, which is still responsible for a large part of the world's morbidity and mortality, was no longer being addressed. Although India has the capacity for the domestic production of drugs to meet all our needs, drug policies favouring multinational companies, as well as the production of a wide range of non-essential drugs, have created the need to import essential drugs. In addition to the issue of production of essential drugs, the other challenges faced in securing the right to essential drugs are irrational prescriptions, endorsement by doctors of irrational drugs, and the presence of spurious drugs in the market.

Amit Sengupta (associated with Delhi Science Forum and AIPSN) continued the discussion on essential drugs, saying that the World Health Organization had developed a list of over 300 essential drugs, addressing the needs of all causes of morbidity in the world. It was felt that these drugs should be affordable and easily available in the market, and should address real medical needs. He expressed the concern that pharmaceuticals often concentrated on selling costly drugs that generated more profits, and those who needed the drugs the most were the least likely to afford the cost. The diminishing price controls, and the trends of pharmaceuticals influencing physician prescription practices also posed a challenge. Patent regimes would cause drug costs to further escalate, causing prices of drugs like the AIDS cocktails to be pushed out of reach of the common man. It was estimated that if the governments of some African countries were to supply medicines for AIDS to their people at current prices, the cost borne by the governments would be many times their GDP.

Other issues that were raised in the discussion that followed were the use of brand names over generic drugs, the inclusion of other systems of medicine prevalent in India, the shift in production from essential drugs to profit-making non-essential drugs, and the need to mandate the production of essential drugs.

2) **Right to Health Care in Situations of Conflict and Displacement**

Key issues related to Right to Healthcare in situations of conflict and displacement:

- There is a glaring need for international advocacy to include intra state conflict as a situation where health services may be denied
- Communal violence in Gujarat led to a complete failure of health delivery
- Health has a number of dimensions in the case of displaced people, in addition to access issues, there is a psychological burden

Amar Jesani: (Working in the field of bioethics) facilitated this session and highlighted the need for guidelines for health services and professionals in the face of conflict and displacement. In his presentation, Dr Jesani contended that guidelines were needed to meet the situational demand, as well as form the basis of law making and future advocacy. He also felt that guidelines should be tools for education, as violations were often the result of fear or ignorance.

There are no formal national guidelines, and the international guidelines set down by the Geneva Conventions do not include situations of "disturbances and tensions, such as riots, isolated and sporadic acts of violence, and other acts of similar nature" as armed conflict. There is a need for international advocacy to include intra-state conflict as a situation where health services may fail to serve the needs of the people. Dr Jesani pointed to a possible number of sources of guidelines and declarations, like those available from the World Medical Association (WMA), the British Medical Association (BMA), the Commonwealth Medical Association, the Amnesty International, etc. He also said that the report of the Human Rights Steering Group of the BMA (2001), "The Medical Profession and Human Rights: Handbook for a Changing Agenda", provided discussions and guidance on similar situations.

He also summarised the guidelines laid down by the International Dual Loyalties Working Group, and concluded by expressing the need for JSA, or one of its constituents, to form a working group to formulate and popularise the guidelines.

Hanif Lakdawalla (associated with Sanchetana, Director Institute for Initiatives in Education) shared with the participants his first-hand experience of the failure of health services during the riots in Gujarat in 2002. He spoke on the issues of access to health care where members of certain religious communities felt unsafe to access care in particular hospitals, where health care providers denied care to people of minority communities, and where prolonged curfew hindered access. The quality of care and record-keeping was compromised, and some providers did not deliver the standard of care expected for victims of sexual assault, or record all findings of assault for patient records and post-mortem reports. Patients of chronic disease like tuberculosis were unable to access hospitals for their medication. Women and children were severely affected because of the failure of the health system. Apart from the psychological trauma, the women in the camps suffered from menstrual disturbances, unsafe pregnancies, and lack of antenatal care, lactation problems, and unmet contraception needs. Children did not receive the required immunization, and many suffered from acute respiratory infections.

Renu Khanna said sexual violence is not acknowledged. She raised the question as how to deal with health in conflict situations, as facilities are absent? She opined violence against women is rampant and there is an urgent need to record it. She said, "We can prepare guidelines for it".

There are many people who want to help and who want support but there are also those who influence violence like police and anti-social elements. According to Ms. Renu, this is one of the main issues on which JSA should focus its attention.

Neha Madhiwalla (associated with CEHAT, working on issues dealing with resettlement) discussed the displacement of slum dwellers and its impact on access to health. She described the impact on access to health care for the residents of Rafique Nagar slum, relocated because of the expansion of the Mumbai airport. Although the relocation included alternative housing, the residents were poorly integrated into the health system. People who were on treatment for chronic diseases found continuity of care a challenge, while women who had developed rapport with local providers for their family planning needs felt they had to create new networks to access care.

Neha also spoke about the urban infrastructure projects, which displace the poor and marginalized, without taking into consideration the possible health implication that is often associated with these "make-shift" displacement. In this situation the dwellers hardly get compensation and alternative housing due to the absence of proper titles and ownership rights. The health implication of displacement was mapped out as follows:

- Psychological impact of dislocation
- Discontinuation of treatment of chronic illness
- Absence of routine health services like immunization, care for deficiency disorders, malaria, and tuberculosis.
- Unavailability of health care during pregnancy, child birth, post-natal period and contraception use
- Additional health problems related to changed establishment

She also cited the that denial to health care occurs because of:

- Lack of proper planning during shifting
- No information provided to concerned institutions
- No additional services are provided
- No temporary measures are instituted

She highlighted that once the people are rehabilitated in a different community

- The socio-political situation creates tension between the local population and new migrants
- The local government machinery views the influx of people as increasing the burden and consequently behaves with hostility.
- The displaced people are disorganized and demoralized. They do not know their local leaders and cannot negotiate in the new surrounding.
- There is a subliminal feeling of loss of citizenship and identity.

Yogini (an activist of Narmada Bachao Andolan) presented the impact on health of the people displaced by the Sardar Sarovar Dam Project. In addition to the psychological trauma and mental stress, which the displaced people suffer from, they have to also face a breakdown of primary health services like antenatal care and immunization because of their relocation. There is rampant malnutrition, frequent outbreaks of waterborne diseases, and malaria.

Dr Jesani, at the end of the session highlighted the lack of health services in times of conflict and displacement; the special needs of vulnerable sections like women and children; the behaviour of the hospital staff and the law enforcing machinery; need for documentation of medical evidence. It was felt that it was imperative to enable health service providers to practice ethically and in a free and fair manner in the times of conflict.

3) Right to Basic Health Services:

Key issues related to Right to Basic Health Services:

- Primary Health Centres provide limited services which concentrate on target based interventions like sterilizations and immunizations.
- There are low levels of motivation amongst the staff due to lack of support and coordination, and frequent unexpected transfers
- There is a shift of budgetary allocation from primary care to tertiary care

T. Sundararaman (associated with BGVS, resource person for Chattisgarh) brought to light the failure of the public health system, and the need for fresh initiatives to overcome some of the lacunae, including poor location of the primary health centres (PHCs), lack of personnel, lack of apparatus, and poorly planned and implemented programmes. He said that the PHCs provide limited services, and concentrate on interventions that can be monitored and are target based, like sterilizations. Levels of motivation among the personnel in these centres are low due to frequent and unexpected transfers, lack of support and coordination between services. The poor infrastructure at the grass- roots level cannot support the implementation of the national health programmes. There is a concern of budgetary allocation moving away from primary health care towards tertiary care, as the government enters private/ public partnerships in building super specialty services, catering to the rich.

Dr. Sundararaman suggested the need for clearly defined norms for services at each level backed by standard guidelines; time-bound budgeted plans, and the role of public participation in health policy advocacy.

4) Women's Right to Health care:

Key issues related to Women's right to healthcare:

- There is rampant irrational intervention like Caesarian sections, hysterectomies
- Women bear the burden of policies like the population policy
- Violence against women needs more consideration as a public health issue
- At present, women's health only includes women in the reproductive age bracket
- The health of Commercial Sex workers needs to be addressed

Manisha Gupte (associated with MASUM, working on women's health) was the moderator for this session in which she emphasized that the discussion covered more than "gender issues" and looked at the effects of religion, marital status, sexual orientation, and situations of conflict and ethnicity on an individual in relation to gender.

Women's safety and welfare ranks low on the priority list of a family. Ms Gupte pointed out that the chances of having a Caesarean section for a woman were directly proportional to the income of the family and the number of contacts with attending doctors and inversely proportional to the gestational risk. Hysterectomies are often performed in the private sector with the view that once the obstetric role of the uterus is over, it is no longer needed.

Women bear the burden of a number of oppressive policies, particularly population policies. In the Public Distribution System, rations are stopped for a third child, and maternity benefits are being denied to mothers with more than two children. These stressors add to the existing stress of pregnancy on women. Issues like violence against women during pregnancy, maternal mortality due to violence, or depression during pregnancy are not even considered.

Women's health, at present, only includes women in the reproductive age bracket; issues regarding the health of girls below the age of 10 and women after 45 are not being addressed. The Pap smear test, allowing early detection and potential treatment of cervical cancer, a major killer, is often not available.
Ms Gupte concluded by saying that the first steps are to ensure basic rights to women, and then move on to issues of sexual health and reproductive health. The right to life, dignity, citizenship and a life free from violence and conflict would pave the way to a right to health.

Jaya Velankar (a women's health activist) echoed the concern that health services for women tended to focus on married women, and on issues related to reproductive health. Social factors related to women's health are not addressed, like the status of women in society, the position in the family context, feeding practices, increased work burden for those women entering the workforce since they have to take care of their household and fulfil different roles at home, etc.

The health of commercial sex workers was not addressed and condoms were still seen as contraceptive devices (again related to reproductive health!) and not vital in preventing the transmission of HIV. Other issues of women's health like violence, women with disabilities, and women's sexual health with regards to homosexuality are yet to be addressed.

The discussion that followed raised some points for consideration. The issue of social discrimination being institutionalised by religious practices as well as government policies was highlighted. The latter was exemplified by the refund of the Rs 500 fine for a third child if the woman underwent a tubectomy! Mortality indicators usually treat women in a generic sense and are not stratified to reflect socio economic differences. The dwindling sex ratio all over the country, particularly the northern states, is an issue that must be addressed with great urgency.

5) **Right to health care for unorganised workers and urban poor:**

Key issues related to Right to Healthcare for Unorganized sector and Urban Poor

- A large part of the sector is made up of women and children, with no access to health benefits
- A number of hazardous professions have no protection
- Dearth of outreach services for the poor and budgetary allocation is very low

Vijay Kanhere (working in the field of occupational health) presented the occupational health problems prevalent in India. He said that in the unorganised sector there was no limit on the working hours, and that government service timings made it necessary for the people working in this sector to take time off in order to access care. People in this sector were not protected by any health benefit plans, nor were there any mechanisms in place to protect them from hazards at the workplace, leading to unprotected exposure to noise, pesticides, chemicals, etc. A large part of the workforce in the unorganized sector is made up of women, who receive no assistance like childcare or maternity benefits.

Bakul Deshpande (associated with IHMP, an organization working in the field of urban health) discussed the issue of urban health services, saying that urban slums were poorly served by the public health system and that the health posts were not situated in the slums. There was a dearth of outreach services provided to the poor and the budget allocation for these services was often very low.

6) **Right to health care for HIV AIDS affected persons:**

Key issues related to Right to health care for HIV AIDS affected persons

- Isolation drives the disease underground-integration is a better way.
- Consent must include pre and post test counselling.
- A person has a right to refuse care.
- State is obliged to provide medical treatment to all persons without discrimination

Anand Grover, an advocate and member of the Lawyer's Collective, stated that it was an established fact that legal and other policies which discriminate and isolate people with HIV, ultimately drive the disease underground, whereas policies which protect these people from isolation encourage them to avail of services thereby curbing the disease. He highlighted the difference between isolation versus integration saying that voluntary testing, a promise of confidentiality and non-discrimination lead to integration. Access to treatment involves certain protocols pertaining to consent, confidentiality, and non-discrimination, access to drugs, and post-exposure prophylaxis. Ensuring the right to health care for people affected by HIV needs a two-pronged approach, to set minimum standards of care while providing services for people affected by HIV, as well as adequate provisions for the safety and protection of people who have occupational risk of exposure to HIV. The issue of confidentiality poses a debate, in which the fundamental right of the spouse to lead a healthy life outweighs the right to confidentiality and privacy. A number of challenges face people affected by HIV, including discrimination in areas of medical care, employment, travel and immigration, services, insurance, etc. Access to drugs, both in terms of availability and affordability, is another obstacle.

Summaries of Plenary Sessions:

a) Health rights in the context of the private medical sector: Ravi Duggal

Right to health in the context of the private sector:

- Private expenditure on healthcare is 1200 billion rupees (5% GDP) compared to public expenditure of 230 billion rupees (1% GDP)
- Lack of price control, poor ethics, practice of kickbacks, multiple systems of medicine present challenges for regulation
- At present the private sector is concerned mainly with curative care with 80% outpatient and 55 % inpatient care delivered through the private sector.
- A publicly financed Universal Health Care system under which the private sector is organized will be a step towards realizing the right to health care in the private sector.

Ravi Duggal (associated with CEHAT and working on health economics), in his presentation stated that in a country where the private expenditure far exceeds the public expenditure, moving towards health care as a right would involve regulating the private sector. Aspects of this sector that make this a daunting task are poor availability of data, presence of qualified and unqualified practitioners, multiple systems with cross practice, the stark rural urban divide, poor registration and standards of hospitals. The private sector has grown, and continues to grow, with 68% of the hospitals in the private sector in 1996 compared to 14% in 1971, and 76% of the doctors in the private sector compared to 68 % in 1971. With lack of price regulations, supply-induced demand, unregulated practice, practice of kickbacks and poor ethics, this sector required regulations at the macro and micro levels. At the macro level, there was a need to take fiscal, legal and professional measures while at the micro level the practice of audits, minimum standards and professional regulation were needed. At present, the private sector is focussed more on curative care. The attempt to rein in the private sector would require the setting up of referral systems, regulation of minimum standards, price controls on drugs and diagnostics, laws regarding emergency medical care, and the standardization of charges in moving towards health care as a right.

b) Right to Mental Health care: Bhargavi Davar

Right to Mental Healthcare:

- Mentally ill are silent victims of custodial abuse in prisons, hospitals and shelters.
- Living conditions are abysmal, residents are often chained
- The staff in mental services is often not qualified in the care of the mentally ill.
- Rural areas have erratic outpatient services and no inpatient services.

Bhargavi Davar (associated with Bapu Trust, working on mental health) stated that mental health and the needs of the mentally ill were a neglected aspect of public health in India. The mentally ill are victims of custodial abuse, both physical and sexual, as well as exploitation by employees, in that they are often made to perform menial and/ or hazardous tasks. This was true of both prison and hospital environments. Hospitals were poorly equipped to meet the needs of the mentally ill and often served more of a custodial role than one of care and treatment. The staff

was not sensitised to the needs of the mentally ill and the doctors were rarely qualified in psychiatry. Living conditions were often abysmal, with low or non-existent standards of sanitation, and patients often being physically restrained with chains. The situation in the rural areas was worse, with erratic outpatient and outreach services and no inpatient services. (One of the hospitals considered in the case study only offered psychiatric outpatient services on the first Thursday of every month!) There was an urgent need for basic care for the mentally ill; however, it was important to bear in mind that this care needed to be care with dignity, another aspect grossly lacking in the delivery of care at present.

c) **Public health sector employees and the right to health care: Kamal Vaykole**

Public Health Sector Employees and the Right to Health care:

- Low budgetary allocations to nursing colleges compared to medical schools are generating many more doctors than nurses, leading to problems in staffing patterns.
- Admission process to nursing schools is fraught with corruption

Kamal Vaykole (a state representative of the Nurses Federation) voiced the various problems faced by the nursing staff in providing services. She stated that nurses formed a part of the health care workforce that was inevitably overworked, but until recently was an unheard voice. The nurses faced a number of challenges: the admission process to nursing schools lacked transparency and credibility; in the workplace, they were faced with shortage of support staff and were often inundated with new technology without being given proper training. This was a fallout of the hi-tech machineries and gadgets purchased by the government, which often suffer from poor maintenance.

d) **Children's right to health care, Vandana Prasad**

Children's Right to Healthcare:

- Anganwadi Scheme, School Health Scheme and Crèche services are not working at the optimum.
- Implementation of two-child norm threatens the rights of the third child.

Vandana Prasad (a practising paediatrician associated with JSA) highlighted the role played by comprehensive services of care for children with the view of keeping them healthy. She expressed concern that the Anganwadi scheme, the School Health Scheme and the crèche services for ailing and working mothers, were not working to the optimum, in terms of the potential for preventive care. The adoption of the two-child norm threatens the rights of the third child in accessing health care, education, and the public distribution system, as well as depriving the infant of its mother's care since maternity leave is not granted for the third child.

As the day drew to a close, the participants exchanged views on the issues raised during the presentations. Some of these discussions among the participants continued over dinner and into the night. While allowing the numerous issues to percolate through their minds and be absorbed, it was also necessary to gear up for the next day's activities, which involved sharing cases of denial, and framing the next steps!

National Consultation on Health Care as Human Right: September 6, 2003

The momentum gathered on the first day of the presentations and dialogues and discussions continued into the second day, when over 300 people congregated for a public hearing and further debate.

The second day of the programme was the National Public Consultation on Health Care as Human Right. NHRC chairperson, Justice Anand, was the chief guest, and cases of denial of health care were presented in the nature of a public hearing.

At the end of the session, all the delegates took a pledge to work towards achieving the Right to Health Care.

In the post-lunch session, there were state-wise discussions on the draft action plan as a follow up to this issue. After that there were brief addresses by all presidium members who belonged to various national networks.

The entire session was ably facilitated by Amit Sengupta.

Welcome address by Dr N.H. Antia:

Dr N.H. Antia, chairperson of Jan Swasthya Abhiyan, in his welcome address, expressed his belief that health was not the monopoly of the doctors alone, and this seminar involved the process of trying to separate health from medicine. He then formally welcomed and introduced the chief guest, Justice Anand, and extended a warm welcome to all the participants.

Inaugural Address by Justice Anand

Justice Anand, started by congratulating the organisers for convening a national consultation on the issue of Right to Health Care and bringing together health scientists, health activists, jurists, policy makers and representatives from every section of the society.
As a background to understanding the issue of Right to Health Care in the international and the Indian context, Justice Anand shared with the audience the following declarations or judgments:

- The **Preamble of the World Health Organization**: Health is defined as "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

- **Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR)** mandates that the states party to the Covenant must recognize the right of everyone to the "enjoyment of the highest attainable standards of physical and mental health."

- The **1978 Declaration of Alma Ata** called upon the nations to ensure availability of the essentials of primary health care, including awareness concerning health problems and the methods for preventing and controlling them; proper nutrition; supply of safe water and basic sanitation; maternal and child health care, including family planning; immunization against major infectious diseases, and prevention and control of locally endemic diseases.

- **The Constitution of India** envisages establishment of a welfare state at the federal level as well as at the state level. In a welfare state, the primary duty of the government is to secure welfare of the people.

- **Article 21** of the Constitution imposes an obligation on the state to safeguard the right to life of every person. It is the constitutional obligation of the state to provide adequate medical services to the people to preserve human life.

- **The Supreme Court:**

In the case of **Consumer Education and Research Centre v. Union of India** [1995 (3) SCC 42]: The government has a positive duty to provide the basic conditions necessary to lead a life that is more than mere animal existence, including a Right to Health, Right to Clean Environment, Right to Privacy.

In the case of **Parmanand Katara v. Union of India** [1989 (4) SCC 286], the Supreme Court said that whether the patient was innocent or a criminal, it was an obligation of those in charge of community health to preserve the life of the patient.

In the case of **Paschim Banga Khet Mazdoor Samity vs. State of West Bengal,** [1996 (4) SCC 37], the Supreme Court ruling, in summary, stated that there must be:

- Adequate medical facilities to give immediate primary treatment to stabilize the patient's condition.
- Upgradation of hospitals at the district level and sub-division level that serious cases can be treated there.
- Facilities for giving specialist treatment at the hospitals at the district level and the sub-division level.
- A centralized communication system so that an emergency patient can be sent immediately to the hospital where bed is available, and where appropriate treatment is available.
- Proper arrangement for ambulance transport of a patient from the primary health centre to the district hospital or sub-division hospital and from the district hospital or sub-division hospital to the state hospital.
- Ambulances, which are adequately provided with necessary equipment and medical personnel.
- Emergency preparedness in health centres and hospitals for larger volumes of patients needing emergency treatment during certain seasons, accidents, or mass casualty.

Challenges in realizing the Right to Health Care can be summarized as: accessibility, affordability, and availability. Justice Anand expressed his disappointment at the efficacy of the National Health Programmes, saying that although more than 41 years have passed since the launch of the National Tuberculosis Control Programme, the prevalence of TB has not decreased. It is said that each minute one person dies of the disease. The National Leprosy Control Programme, a few decades old now, has been unable to reduce the prevalence of the disease, giving India the dubious distinction of housing 61% of the world's leprosy patients.

At present, services are hospital based, disease oriented, and place emphasis on curative care. This basically serves the wealthier sections at the expense of providing universal comprehensive primary care.
Justice Anand reiterated that the 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 and must do whatever is necessary..

The NHRC has taken a series of initiatives towards establishing health as a human right. In earlier annual reports it was noted that low social indicators were often associated with increased incidents of human rights violations. For example, in states like Uttar Pradesh, Bihar, Orissa, and Madhya Pradesh where literacy rates are barely 50%, and worse for women, 35% of the population live below the poverty line and infant mortality rates vary between 75 and 96 per thousand. The Commission receives the most number of complaints from areas like these, for a host of violations of civil, political, economic, social and cultural rights. Justice Anand compared these findings to those of Kerala, where with 90% literacy, the infant mortality rate is only 16 per thousand (comparable to Western countries), and an alert civil society addresses human right violations.

In keeping with its broad objective to give greater practical meaning to the right to health care, the Commission organized three major national consultations in 2000-2001. The first was a Workshop on Health and Human Rights, with special reference to Maternal Anaemia, which was held in New Delhi on April 26-27, 2000. The second was a National Conference on Human Rights and HIV/AIDS, jointly organized by the Commission with the National AIDS Control Organization, Lawyers' Collective, UNICEF and UNAIDS, which was held in New Delhi on November 24-25, 2000. The third was a Regional Consultation on Public Health and Human Rights.

Justice Anand called upon civil society to strengthen itself, and to involve more of the "public" in public health. He stressed the need for innovation as opposed to imitation. He concluded with a much appreciated 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."

Public Hearing of Cases of Denial of Health Care:

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

- Sucheta Devi was motivated by the auxiliary nurse midwife to undergo sterilization at the tubectomy camp in Halharmau Primary Health Centre, in Uttar Pradesh. She was made to sign papers, but not explained their contents. Although the procedure is a minor and routine one, she passed away during the operation. The relatives of the deceased were not informed of her death, and all the staff, including the doctor left the centre. Members of her family found her dead body on a stretcher outside the operation theatre.

- Anita, a 12-year-old girl, from Malakapur was bitten by a rabid dog. She was taken to the district hospital in Moradabad, but not given the anti-rabies vaccine. She died after a few days. Three others from the same village, who had also been bitten and were denied the vaccine, succumbed to rabies.

- Namdeo, a resident of Thane district was bitten by a snake. He was first taken to the primary health centre in Saralgaon, Maharashtra, where, for non-availability of anti-snake venom, he was referred to the Murbad Rural Hospital. The rural hospital did not have the anti-snake venom in stock either, and his relatives were advised to purchase the medications from a private pharmacy. After procuring the medicines, he was asked to wait in line, instead of being seen on an emergency basis. Namdeo died the same day.

- One-year-old Asha, a resident of Mokhada, Thane district, Maharashtra, had fever and difficulty in breathing (pneumonia). Two visits to the primary health centre (PHC) proved futile, as there was no doctor. They finally went to another PHC, where the doctor told them that there was no bed for the child. She was placed in a house neighbouring the PHC, where she was being treated. After the doctor left, there were no trained personnel and the baby died that night.

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

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

Legal and Constitutional Entitlements for the Right to Health Care:

Professor Satyaranjan Sathe, former principal of the Pune Law College and a constitutional expert, described those "heart rending" cases and said that they were examples of the failure of the State, civil society, democracy and bureaucracy. He stated that the problem did not lie in the lack of rights but in the lack of enforcement of these rights. Although a perusal of Supreme Court rulings would create the illusion that the state of rights in India was ideal, the stark reality was that only a few people had these rights.

As a result of liberalization, privatization and globalization, the State was increasingly abdicating from its primary duty as a welfare state and was negligent in the duty of providing primary education and primary health to its people. The State was actually working against the definition of a welfare state as defined in Article 38 of the Constitution.

According to Professor Sathe, the Right to Health had many elements, which include the right to access to nutrition, sanitation, water, healthy environment, and health care.

Professor Sathe highlighted the rural-urban disparity. CEHAT data showed that there were 15 times the number of beds in urban areas as there were in rural areas (3.0 per 1000 urban population compared to 0.2 per 1000 rural population), 5 times the number of doctors in urban areas (3.4 per 1000 urban population compared to 0.6 per 1000 rural population), and 7 times the per capita public expenditure in urban areas (Rs 560 per capita in urban areas compared to Rs 80 in rural areas).

The Right to Health Care involves three components: The State, the market, and civil society. Under the Nehruvian vision, the State was responsible for everything and would look into the needs of its people. This resulted in a strong bureaucracy and a weak civil society. This weak civil society had to be strengthened as the State gradually withdrew from its field of duty. It must also be prevented from withdrawing altogether since the State was required to control the market. The responsibility for driving the State to fulfil its duties lay with civil society.

India had the most privatized health sector in the world, more than the private health sector in capitalist countries. A shocking 83% of expenditure on health was borne by the consumers and a mere 17% by the State. This had the greatest negative impact on the poor. He cited a ruling by the Supreme Court, in favour of the T.M. Pai Foundation in which the court granted private medical colleges the right to charge medical education fees as per their discretion, thereby allowing fees to escalate as per market forces. The result was that only the rich could afford medical education, and that people became doctors based on their buying power and not aptitude or intentions. The degradation of the medical profession was further fuelled by the lack of action against errant doctors. There was little litigation against injustice and victims often keep quiet in the face of rights violations.

Like all rights, the Right to Health Care could not be realized with judicial intervention alone, but required tremendous action by civil society. Dr Sathe, illustrating the limitation of law said that although the law could prevent a person from being bad; it could not make a person good. The law was only a part of the social framework within which the right to health care could be realized. The other integral part was civil society, which now needed to be strengthened through education, and a consciousness of the value of human life. At present, the death of humans due to disease, conflict, hazardous occupations, etc, was taken too lightly.

He recalled President Abdul Kalam's statement that future generations would not judge us by the number of mosques or temples we built, but how far we could provide clean water and help solve peoples' problems.

Professor Sathe concluded by saying that public movements were a ray of hope. The road to Right to Health Care was fraught with a number of challenges, but we must each become a Gandhi ourselves, and struggle.

Dr Abhay Shukla made a brief and systematic presentation about the view taken by JSA towards the Right to Health Care. He pointed out that a number of developed countries had made universal health access possible within a market economy. It was a strongly felt need that India should move towards such a system of health care through health care reforms and legally enforceable entitlements. He mentioned the recommendations following the Workshop held in 2000, in which, the NHRC has recognized that the Right to Health Care be translated to a fundamental right, with the necessary constitutional amendment to this effect.

It was unfortunate that senior government officials were unable to attend the programme as promised, and participate in the hearings, and the subsequent discussions.

A vote of thanks was proposed by T. Sundararaman and gratitude expressed to Justice Anand and Professor Sathe for their presence and illuminating inputs to the programme.

The session ended with all the participants taking the following pledge in the presence of Justice Anand:

> *"On this day, the 6th of September 2003, on the occasion of the 25th Anniversary of the historic 'Health for All by 2000 AD' declaration, we as national representatives of Jan Swasthya Abhiyan, take the following pledge --*
>
> *We regard the right to the highest attainable standard of health as an inalienable human right. We declare that the Right to Health Care should be made a Fundamental Right in the Indian Constitution, and that this right must be enforced immediately through appropriate legal and executive measures.*
>
> *We pledge to work tirelessly to resist the denial of this right in all forms and at all levels, and to mobilize our fellow countrymen and women towards the establishment of the Right to Health Care as an important milestone on the way to the realization of the dream of 'Health for All."*

The group then took a break for lunch, which provided time and opportunity to continue the process of catching up with old friends, and meeting new ones. Over lunch, the events of the programme so far were discussed and everyone seemed recharged and eager to get back into the hall for the next session.

State-wise Group Discussions:

The post-lunch session was an opportunity for participants from different states to meet their fellow activists and discuss how to take the campaign forward in their respective states. The states represented were Andhra Pradesh, Bihar, Chattisgarh, Delhi, Gujarat, Himachal Pradesh, Jharkand, Karnataka, Kerala, Madhya Pradhesh, Maharashtra, Orissa, Rajastan, Tamil Nadu, Uttar Pradesh and West Bengal. Dr T. Sundararaman handed out a set of guidelines for action to be taken at each level, and groups brainstormed on how to implement them locally. A summary of the guidelines presented by Dr. Sundararaman and steps highlighted by Dr Abhay Shukla in his presentation, are as follows:

Future steps for JSA--What we need to do to make the Right to Health Care more than an ideal dream...

District Level

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

- **Documenting** cases of denial
- **Compiling** cases of denial for presentation with the help of sensitized medical professionals
- **Collecting** basic data gaps in the infrastructure and staff
- **Identifying** gaps in quality between standard norms and available services.

⇩

Public Hearings on Health in about 300 districts

⇩

Actions:

- **Demanding** representation in district, block and village level.
- **Closing** gaps in infrastructure and staffing.
- **Implementing** quality norms.

The district public hearings must then lead to public interest litigations and regional NHRC public hearings. Vice versa, the public hearings also use the context created by such action the national and state level to strengthen intervention at the district level.

State Level

JSA must be strengthened as a forum for policy intervention

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

National Level

- Releasing the book "State of India's Healthcare Services" during the People's Health Assembly anniversary week in state capitals and in the media.
- Preparing general guidelines for situational analysis on Health policy as relating to Right to Health care in each state.
- Continuing documentation of denial of health care and submission to NHRC.
- Arranging for Regional Hearings on Denial of Right to Health Care.
- Filing Public Interest litigation in key areas, such as right to basic health services, women's right to health care, right to essential drugs etc.- March 2004
- Interacting with parliament and legislatures - March 2004
- Moving towards making the Right to Health Care a Fundamental Right in the Constitution
- Working towards Patient friendly redressal mechanisms
- Developing Guidelines on range of costs for standard services
- Involving diverse social sectors in a dialogue on the Right to Health Care

Taking the Campaign and JSA forward:

The final session consisted of a series of detailed presentations made by members of various national networks. Father Sebastian (CHAI) made a presentation on the programme organized by CHAI on the " Universal Access to Health Care", on the occasion of the diamond jubilee of CHAI. Other presentations included Joe Varghese (CMAI), Sonia Gill (AIDWA), Suhas Kolhekar (NAPM), R.K. Padma (Joint Women's Programme), Amitava Guha (SMRAI), Prasanna Saligram (AID), Shanta Ranade (NFIW), Sarojini (MFC) as well as representatives of AIPSN and FMRA.

Conclusion

It is said that a journey of a thousand steps must begin with one. The programme on the 5th and 6th of September marks the initial steps in achieving "Health Care for All--Now!" In the face of liberalization, privatization and globalization, transforming, "Health for All--Now!" from an ideal to a reality, is by no means an easy task. However, the enthusiasm and the resolute response from the grass-root activists and the strong leadership and able direction of the JSA give one the hope that the matter will be pursued to its logical conclusion.

Annexure 1

Brief Note on Types of Cases of Denial of Health Care

Till now total 70 cases have been collected from various states of the country regarding denial of health care in the public health care facility. To identify the exact nature of denial in all these cases, they were categorised as per type of case, type of denial and the consequence of denial. The aim of collecting these cases is not to focus on the behaviour of the health personnel but is to pinpoint the lacunae in the existing health services at various levels such as infrastructure, manpower, essential equipment and essential medicines etc.

The categories of type of case were as follows:

1. Women's health conditions which mainly included delivery, abortion and family planning services like Copper T insertion and tubectomy.
2. Treatment of communicable diseases- here mainly cases included patients suffering from Tuberculosis, jaundice, diarrhoea etc.
3. HIV positive patients or patients suffering from AIDS
4. Emergency conditions like accidents, dog bite, snakebite, burns etc.
5. Child health problems
6. Treatment of chronic illnesses like hypertension, diabetes etc.

In all these cases, the denial was of following types:

1. Required human power not available at the time when the patient is taken to the health care facility.
2. Medicines not available or in some cases patients were asked to replace the medicines used for the patient during his/her stay in the hospital.
3. Patients referred outside for doing investigations.
4. Rude behavior of the staff
5. Delay in treatment
6. Charging the patient more than specified
7. Unavailability of the transport facility to refer the patient to higher facility
8. Non-availability of the essential equipment required for the treatment
9. Negligence of the health staff

There are four types of consequences of these denials. They are as follows:

1. Death
2. Permanent damage leading to handicap
3. Moderate financial loss
4. Mild financial loss

Type of Case

The table given below shows that out of the total 70 cases collected almost 30% cases are those where women have been denied health care for conditions such as delivery, abortion and contraceptive services. First of all in our setup women find it very difficult to access the health care services. Those who overcome these difficulties and reach in the hospital are turned away by the health personnel on the pretext of non-availability of essential equipment or medicines etc.

Second majority of cases is of those who are suffering from non -communicable diseases followed by communicable diseases.

Type of case	Number of patients
▪ Women's health conditions which mainly included delivery, abortion and family planning services like Copper T insertion and tubectomy.	25
▪ Treatment of communicable diseases- here mainly cases included patients suffering from Tuberculosis, jaundice, diarrhoea etc.	10
▪ HIV positive patients or patients suffering from AIDS	4
▪ Emergency conditions like dog bite, snakebite, burns etc.	7
▪ Child health problems	8
▪ Treatment of chronic illnesses like hypertension, diabetes etc	16
▪ Women's health conditions which mainly included delivery, abortion and family planning services like Copper T insertion and tubectomy.	25
▪ Treatment of communicable diseases- here mainly cases included patients suffering from Tuberculosis, jaundice, diarrhoea etc.	10
▪ HIV positive patients or patients suffering from AIDS	4
▪ Emergency conditions like dog bite, snakebite, burns etc.	7
▪ Child health problems	8
▪ Treatment of chronic illnesses like hypertension, diabetes etc	16

Type of Denial

Type of Denial	Number of Patients
▪ Required human power not available at the time when the patient was taken to the health care facility	6
▪ Medicines not available or in some cases patients were asked to replace the medicines used for the patient during his/her stay in the hospital.	34
▪ Patients referred outside for doing investigations.	20
▪ Rude behavior of the staff	12
▪ Delay in treatment	31
▪ Charging the patient more than specified	8
▪ Unavailability of the transport facility to refer the patient to higher facility	6
▪ Non-availability of the essential equipment required for the treatment	16
▪ Negligence of the health staff	10

Here for one case there are different types of denial for eg. A patient of snakebite when taken to the hospital is not attended immediately. After that there is no vaccine in the PHC therefore he is referred to the CHC, but there is no ambulance for taking the patient,. Thus in this single case there are three different types of denial seen. The table shows that in 50 % cases the patients were asked to bring the medicines from outside and the delay in treatment is reported by the patient or the relatives whereas in one third cases the patient has been referred outside for investigations. In 10 % cases, required human power was not available in the Government health facility, there was no facility of taking the patient to another hospital and the charges were mote than prescribed.

Analysis of Cases of Denial

	Women's health problems	**Communicable diseases**	**Diseases related to HIV infection or AIDS**	**Emergencies like snakebite, dogbite, burns etc**	**Child health problems**	**Chronic illness**
Required Human power not available	2	0	0	1	2	1
Medicines not available	8	7	1	3	3	11
Investigations not done	5	4	3	0	0	8
Rude behaviour of staff	6	0	2	0	1	3
Treatment not given on time	11	2	2	3	4	9
Charges more than specified	2	2	0	1	0	3
No transport facility available	2	1	0	1	0	2
Non availability of essential equipment	8	1	0	0	2	5
Negligence in the treatment	9	0	0	0	1	0

The table shows that in case of female patients the rude behavior of the health staff has been reported most commonly, similarly negligence in treating the patient is also reported more in case of female patients.

Consequence of Denial

Type of consequence	Number of patients
Mild financial loss	17
Severe financial loss	29
Permanent damage leading to handicap	2
Death	22
Total	70

Out of total 70 cases collected, death has taken place in 22 patients which means in almost one third cases the denial of health care has led to serious consequence. Where as the second most common consequence is severe financial loss. It was seen that when a patient is denied health care in the public facility, the patient is taken to the private hospital in order to save his life, thus the families have to bear severe financial loss in the form of debt.

Annexure 2

List of Organisation whose members attended JSA Programme on 5th and 6th September 2003

1. ACASH
2. Adivasi Mukti Sangathan
3. Association for India's Development- (AID) India
4. All India Democratic Women's Association (AIDWA)
5. All India Drug Action Network (AIDAN)
6. All India People's Science Network (AIPSN)
7. APNALAYA
8. Asha Mahila Sanstha
9. Association for People Living With HIV/ AIDS
10. BCM hospital, Sitapur
11. BGVS -Bharat Gyan Vigyan Samiti

    State units-

    - Madhya Pradesh
    - Jharkhand
    - Chhatisgarh
    - Bihar
    - Uttar Pradesh
    - Rajasthan
12. Bharat Gyan Vigyan Samuday – Maharashtra
13. Catholic Health Association of India (CHAI)
14. CCDT
15. CEAD- Andhra Pradesh
16. CED
17. Centre for Advocacy in Mental Health (CAMH)
18. Centre for Enquiry into Health and Allied Themes (CEHAT)
19. CHAT- Catholic Health Association of Tamilnadu
20. Christian Medical Association of India (CMAI)
21. Community Health Cell (CHC)
22. Delhi Science Forum
23. Dilaasa, Cehat
24. Disha Kendra, Karjat
25. Eklavya, MP
26. Explorations, Mumbai

27. Federation of Medical Representative Associations of India (FMRAI)
28. Forum for Medical Ethics (FME)
29. Halo Medical Foundation
30. Healing Touch
31. Health watch – UP Bihar
32. HGVS (Himachal Pradesh Gyan Vigyan Samiti)
33. IIT Chennai, Department of Humanities and Social Sciences
34. India Centre for Human Rights and Law
35. Indian People's Tribunal on environment and human rights
36. Institute of Health Management, Pachod
37. Institute of Health Management, Pune
38. Institute of Immunoheamatology, KEM hospital Vadodara
39. Institution of Engineers, Jharkhand
40. Jan Jagruti Kendra
41. Jan Swasthya Sahyog
42. Jan Vignyan Vedika
43. Janarth Adivasi Vikas Sanstha
44. Jansastha Chetana Prasar Samiti, West Bengal
45. Janwadi Mahila Sanghatana (All India Democratic Women's Association)
46. Jaslok Hospital
47. Joint Women's Programme (JWP)
48. K B Bhabha Hospital
49. Kagad Kach Patra Kashtakari Panchayat
50. Kashtakari Sanghatana
51. Life Health Reinforcement Group
52. Lokshakti Samiti
53. Madhya Pradesh Vigyan Sabha
54. Madhya Pradesh Voluntary Health Association
55. Maharashtra Government Nursing Federation
56. MASUM
57. Medico Friends Circle (mfc)
58. Narmada Bachao Andolan
59. National Alliance Of People's Movement (NAPM)
60. National Centre for Advocacy Studies
61. National Education Welfare Society
62. National Federation of Indian Women

63. Paschim Bang Vigyan Manch, Calcutta
64. Prayas, Rajasthan
65. Prerana
66. Rationing Kriti Samiti
67. Sahaj, Baroda
68. Sama, New Delhi
69. SAMPARK Mumbai
70. Sampark, Jhabua
71. SANGRAM
72. Sankalp Rehabilitation .Trust
73. Shanti Avedana Ashram
74. Shramik Mukti Dal, Aajara
75. Shramik Mukti Sanghatana
76. SNEHA
77. State health Resource centre, Chhatisgarh
78. Tathapi Trust
79. The Humanity
80. TNSF (Tamilnadu Science Forum)
81. Trust for Reaching the Unreached- TRU Baroda
82. Wanless Hospital, Miraj
83. WDC, Mumbai University
84. Women Centred Health Project-BMC
85. Women's Centre, Mumbai
86. Women's Research and Action Group
87. Women's Studies Unit, Tata Institute of Social Sciences, Mumbai
88. YUVA