

A World Where We Matter!



Towards the Peoples Health Assembly Book -4

A World Where We Matter!

*Prepared and published by
The national co-ordination committee
for the*

Jan Swasthya Sabha



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A World Where We Matter!

First Edition July 2000

Authored and Published by:

National Coordination Committee, Jan Swasthya Sabha

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All India People's Science Network (**AIPSN**);
All India Democratic Women's Association (**AIDWA**);
All India Drug Action Network (**AIDAN**);
Association for India's Development, India (**AID-India**);
Breast Feeding Promotion Network of India (**BFPNI**);
Bharat Gyan Vigyan Samiti (**BGVS**);
Catholic Health Association of India (**CHAI**);
Christian Medical Association of India (**CMAI**);
Federation of Medical Representatives and Sales Associations of India (**FMRAI**);
Forum for Creche and Child Care Services (**FORCES**);
Joint Women's Programme (**JWP**);
Medico Friends Circle (**MFC**);
National Alliance of Peoples' Movements (**NAPM**);
National Alliance of Women's Organisations (**NAWO**);
National Federation of Indian Women (**NFIW**);
Ramakrishna Mission (**RKM**);
Society for Community Health Awareness Research and Action (**SOCHARA**);
and
Voluntary Health Association of India (**VHAI**).

Participating Organizations

Over 1000 organizations concerned with health care and health policy from both within and outside the above networks, have joined the Jan Swasthya Sabha campaign as participating organizations.

About the Jan Swasthya Sabha

Governments & international agencies have forgotten the goal of Health for All by 2000 A.D. But we the people cannot forget it. It is time to strengthen & expand people centered initiatives - to find innovative solutions & to put pressure on decision makers, governments and the private sector.

There is a need to reiterate that attaining Health for All means ensuring everyone has access to affordable quality Medicare. Safe drinking water and sanitation, adequate nutrition, clothing, shelter and employment and no one is discriminated against on the basis of class, caste, race or gender. People need to be made aware of the links between globalization and the. Worsening health of the people when structural adjustment policies work to underline the vision of Alma Ata, renewing the Health for All call is an imperative.

With this understanding, a large number of people's movements across the country have jointly initiated a national campaign called the Jan Swasthya Sabha. This has three broad objectives:

- * To re-establish health and equitable development as top priorities in policy making with primary health care as the strategy.
- * To forge a local, national and global unity of all democratic forces to work towards building long term sustainable solutions to health.
- * Reinforce the principle of health was a broad inter-sectoral issue

The campaign has a four-tier structure. 2000-3000 blocks in 200-300 districts mobilize people on Health For All - Now! and conduct block level enquiries into the state of health services. These enquiries culminate in block seminars highlighting the findings & helping formulate people's initiatives for primary health care. Then, each district has a district level mobilization culminating in a District Seminar. All this builds up to the Jan Swasthya Sabha to be held in Calcutta from Nov 30th - Dec 1st 2000. Four trains with representatives from various parts of the country will arrive at the National Assembly. The Jan Swasthya Sabha - with over 2000 representatives - will call for a reversal of structural adjustment policies and a renewal of the *Health for All* pledge. The assembly will also send its representatives to the international People's Health Assembly being held at Dhaka from Dec 4th - 8th, 2000 ~here similar representatives from other countries will gather. Following the Jan Swasthya Sabha, each interested block or district follows up with health intervention and advocacy. The Jan Swasthya Sabha is being coordinated by a National Coordination Committee consisting of 18 major all India networks of people's movements and NGOs. This book is the fifth book in a 5 book series brought out by the NCC for guiding the block, district and state seminars.

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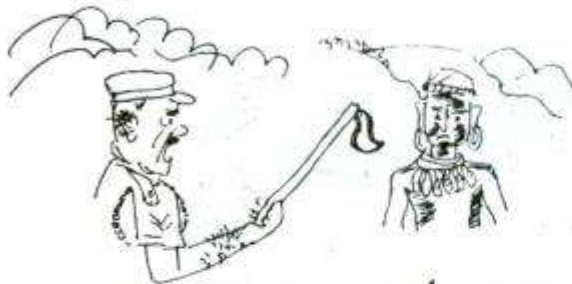
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Chapter 1

The Marginalized and the Vulnerable

Get out! Don't you know this has been declared a reserve forest?

No restrictions on milk product imports! No more protection for cottage industries!



You must use this injectable contraceptive. It is part of the national scheme.

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

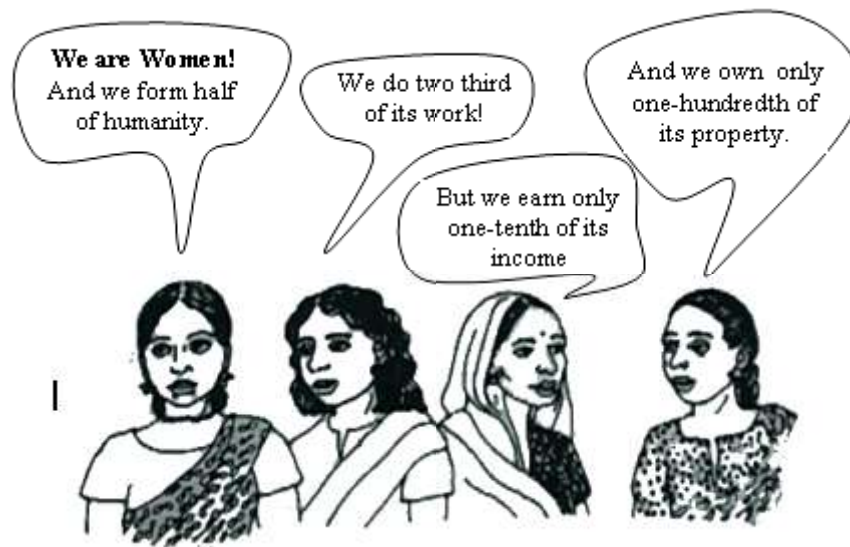


But nobody even asked us! This hurts us! We need...

A World Where We Matter!



In our society, affluent upper-caste males usually make all the decisions. Even if they want to be fair, as long as the process of decision-making is not participatory, they land up assuming that their perception of needs and their sense of values is the same as that of the entire society. (And very often they don't want to be fair!)



Our health needs differ from men's in many ways.

We must have a world where we are heard - A World Where We Matter!

**We are Children!
We have Special
needs too!**

**Particularly
Children of
the Poor and
the Girl Child**



**Biologically
we are more
vulnerable to
Disease**

But some of us who
have been robbed of
our childhood are even
more vulnerable!



**Working
Children**

**Children in
carceral
institutions**

**Street
Children**

**We are not responsible
for our situation - you
are! It is your duty to
give us special attention!**

**Children in
wars & disasters**

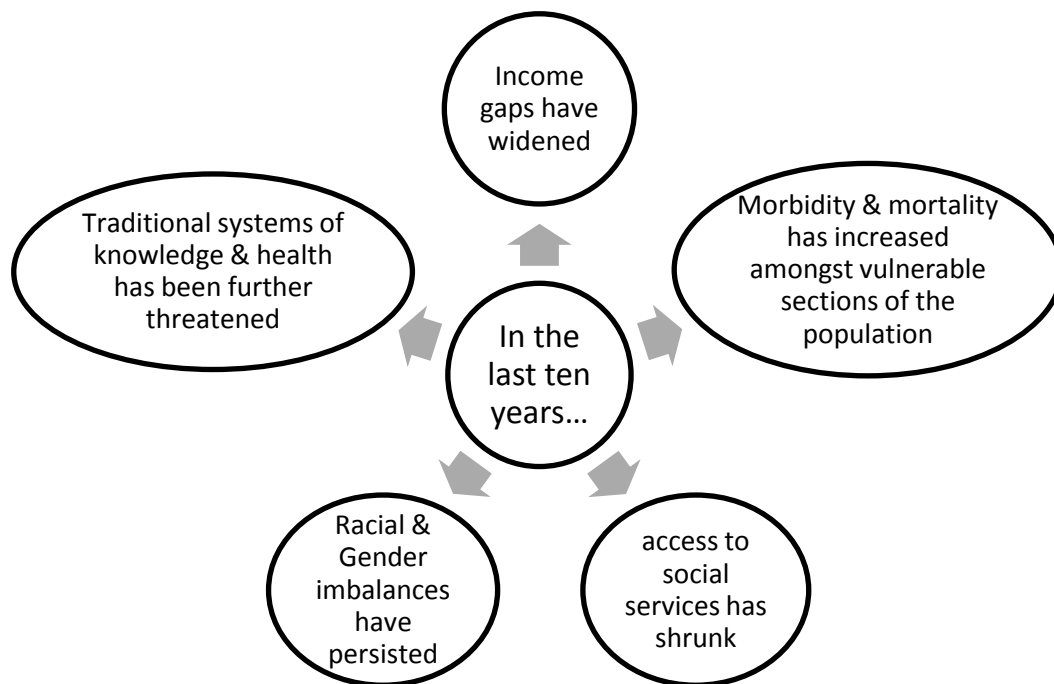


And that's not all!

We are Dalits, Adivasis, Prisoners, Unorganized Workers, Commercial Sex Workers, Beggars, AIDS and Leprosy Patients, Mentally ill, Disaster and War affected and many many more!

And we want a world where WE matter!

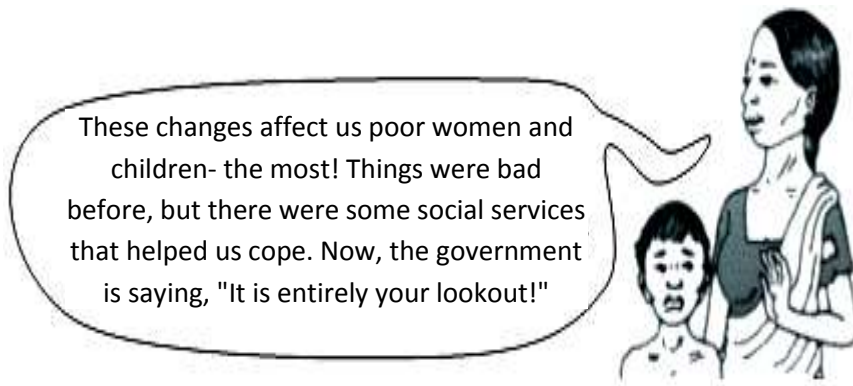
How Structural Adjustment affects Women and Children



Within the health sector there has been a failure to implement the Primary Health Care policies. The main deficiencies include:

- a) A retreat from goal of national health and drug policies
- b) A lack of insight into inter-sectoral nature of health
- c) A failure to promote genuine involvement of communities

- d) An inequitable privatization policy reducing state responsibilities.
- e) A narrow top-down, technology oriented view of health



Chapter 2

Women's Health

Focusing on the Poor



What is our health status? How does it compare with that of men? What are the reasons for the difference? Let's now look at some of the issues...

Women are more prone to death and disability!

Just Look at the Sex Ratio!

The sex ratio is already low, and declining! It now stands at 929 women per 1000 men. In 1941 it was 945 per thousand. Even in a state like Tamilnadu which seems to be doing better with a sex ratio of 972 per thousand we see that even here there has been a decline from 1012 in 1941 to the present level! How's that for proof!

What is the proof?



In most developed countries, the ratio is over 1000 women (about 1010) for every 1000 men. This means if anything, biologically women have a small advantage in terms of longevity & survival. But the Indian situation is reversed - till the age of 45, women face a greater risk of death than men.

The risk of death is greatest during the child-bearing years when deaths associated with pregnancy add on to other causes. In India today the

Or Look at the Maternal Mortality Rates....



maternal mortality rate is over 400 per lakh. This is as compared to less than 10 per lakh in the entire developed world. This means that about 390 of these 400 deaths are potentially preventable.

Imagine! Half a lakh preventable deaths every year in childbirth alone!



State	Sex Ratio	Maternal Mortality	Infant Mortality
Andhra	972	436	66
Arunachal	861	-	47
Assam	925	554	78
Bihar	912	470	67
Goa	969	-	23
Gujarat	936	389	64
Haryana	874	436	69
Himachal	996	456	64
J&K	923	-	45
Karnataka	923	450	58
Kerala	1040	87	58
Madhya Pr	932	711	98
Maharashtra	936	336	98
Manipur	961	-	25
Meghalaya	947	-	52
Mizoram	924	-	23
Nagaland	890	-	NA
Orissa	972	738	98
Punjab	888	369	54
Rajasthan	913	550	83
Sikkim	880	-	52
Tamilnadu	972	376	53
Tripura	946	-	49
Uttar Pr	882	624	49
West Bengal	917	389	53
All India	929	543	72

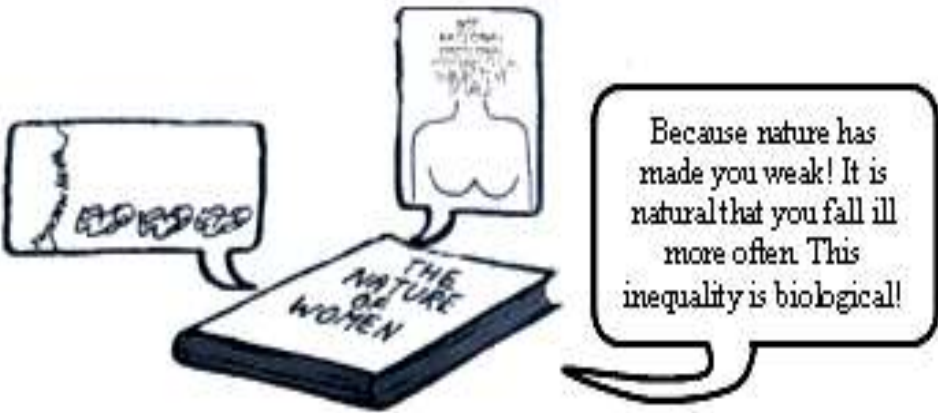
Source: Sex Ratio is based on the 1991 Census, Maternal mortality on UNICEF's reports and the Infant Mortality Rate is from the National Population Policy Annexure and is based on Govt. Statistics 1998.

Women's morbidity, is higher than of men. In one study in rural Maharashtra (by FRCH) the difference seen was 730 women as compared to 513 men were sick at any given point of time (i.e, 19.7 women and 13.8 men per 1000 population). Not surprisingly, other health indicators such as levels of anaemia and malnutrition among women remain unacceptably high. Almost all women are anaemic.

Or look at the morbidity rates!



Why are we more prone to death and disability ?



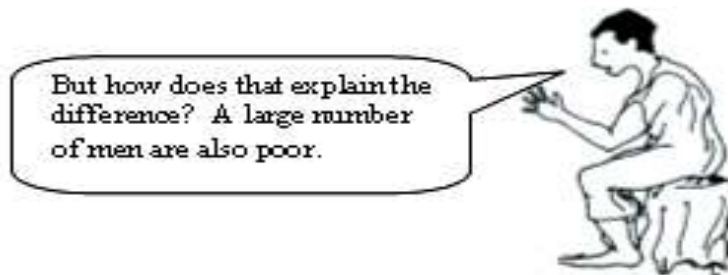
No!
That's a rotten theory - our poor health is not biological!
The real answers lie not in the patriarchy of nature but in the nature of patriarchy!





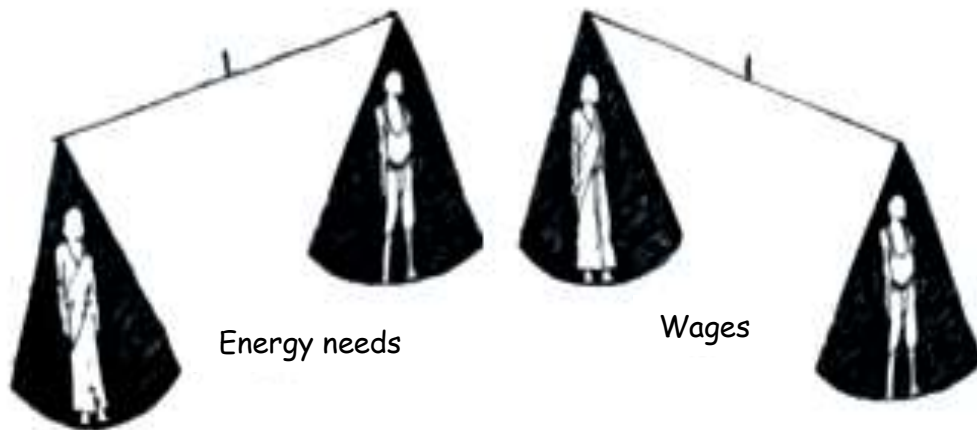
The real reasons for the difference in health status...

A sizeable proportion of women (30-40%) by official estimates live below the poverty line.



True! But poverty affects women the most. Particularly women - headed households!

Because of migration, desertion or death or factors like alcoholism, almost one third of households in rural areas are effectively woman headed! In such households the major income, often the only income is from the women's wages. Since women are paid less and since they prioritize others' food needs over their own, women in such households are malnourished & in considerable suffering! And so they fall ill more often leading to even less earning and further suffering!



Women are paid less than men for the same work and usually hired only for lower rated work, (eg weeding) which are called women's work though they may be as strenuous! And most women's work is in the unorganized sector, where there are no maternity benefits and no savings provisions and where working conditions are abysmal.

And now more and more, under structural adjustment policies, the only employment available to us is in the unorganized sector. And even in this sector the profits and jobs are rapidly declining as we have to face competition from global multinationals!



Being poor we are likely to have more children, many of them below normal birth weight or still born or aborted.

Frequent childbirth, early childbirth and excessive childbirth is a major cause of ill health of poor women. To the poor, children are the only savings for the future. In a patriarchal society only the male child matters. Given the high infant mortality rates, and the high rates of still births and abortions, to be sure a male child survives a woman is often forced to have 5-6 children to be reasonably sure of having a surviving male child during their old age. At any rate the bearer of the child has little say on the decision to have a child.



If this decision was in my hands and I was reasonably sure my children would survive why would I have more than 2-3 children?..

So many pregnancies and the accompanying morbidity leave women too weak to fully participate in society.

We women are also susceptible to a variety of physical sicknesses. And most of this can be prevented!



Tuberculosis for instance is one of the greatest killers of women. For every woman dying during pregnancy about 4 die of tuberculosis! The weakened malnourished and anaemic bodies of women are much more likely to get tuberculosis than a healthy person. Urinary tract infections are commoner in women. Women are more likely to get HIV! And of course all pregnancy related diseases affect only women!

We do exhausting work at home in poor environmental conditions. And at work, we have the dirtiest, most tiring jobs with inadequate remuneration and rest.

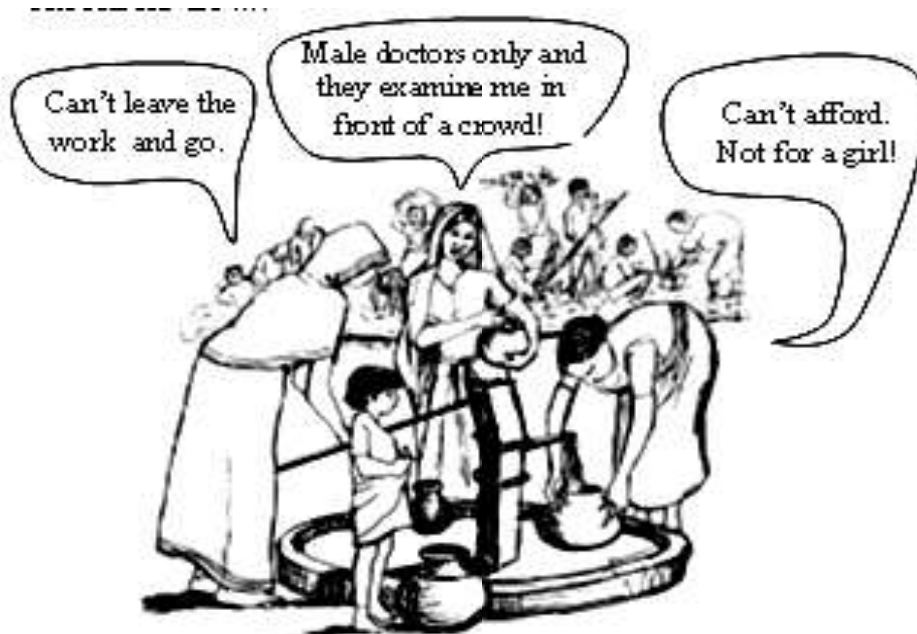


Women have neither weekends nor holidays! Just the sheer exhaustion of over work along with the poor conditions of living and working is enough to cause disease. In the house, the kitchen and the woman's space is often the poorest. Privacy is inadequate and toilets non-existent. The work place is usually cramped with no special understanding of a women's needs. Because men make the workplace though women work in it.

Women have lower levels of literacy, and less access to existing health care services.

For the same level of illness a girl child, an adolescent girl or a young woman is less likely to go to a health centre than her male counterpart. The reasons are

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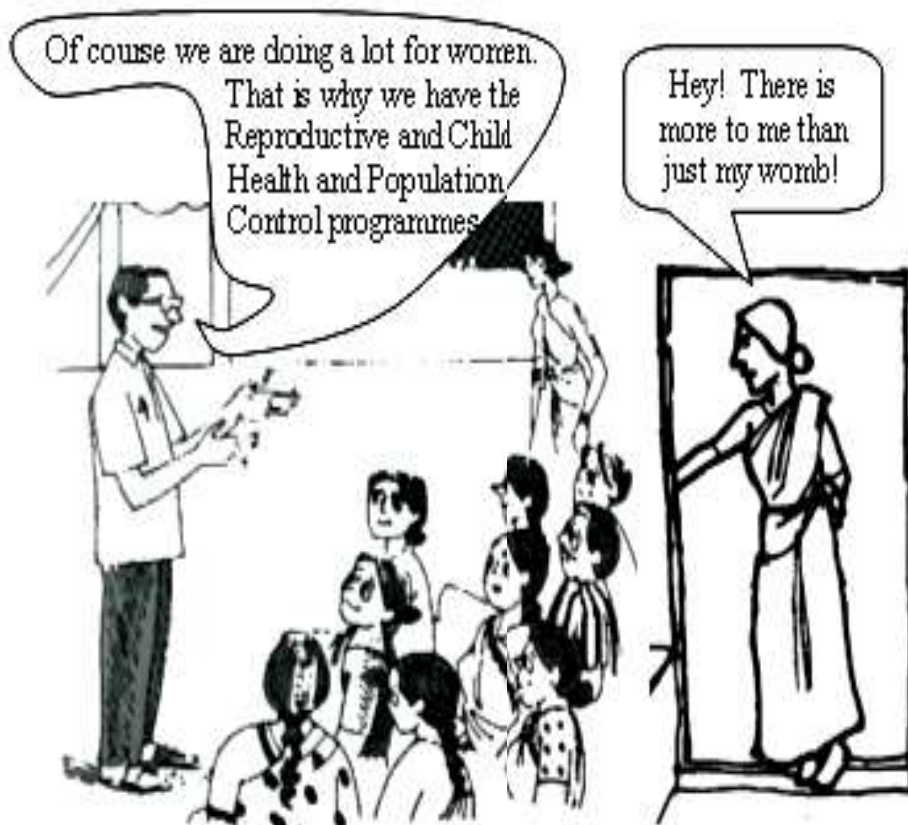


And many more reasons including shame & lack of information. These issues affect even educated women, though to a relatively lesser degree.

Life in this situation makes for a poor self-image, low self-esteem, low self-confidence and unrecognized emotional problems caused by crises.



But do health programmes address these issues?



In India, Health programmes for women continue to focus almost exclusively on our reproductive or child-bearing function. Sometimes they mention the girl child or the adolescent girl but often these are more in the form of token gestures. !

This is an old problem - the way a patriarchal society values women only for her child bearing role! It is also a new problem - the state trying to control the population and targeting women's bodies as the easiest way to achieve it.



The Challenge - How to define what women's health is all about?



Our Health Ourselves!

The foundations...

1. We are human beings situated in society and our health has to be viewed through an integrated holistic approach. Several medical, societal, socio-economic, political and cultural factors determine our health status.
2. Our value as a human being of dignity and worth needs to be emphasized. This has to be delinked from reproduction or production of any type.
3. Our total health needs in the context of our circumstances should be considered. Positive indicators of physical, emotional, intellectual and social health should be used.
4. Periods of crisis in women's lives should be recognized.
5. While a woman's reproductive system influences the functioning of her body and may be a cause for ill health, we suffer from other diseases as well! Availability and access to good basic and comprehensive health services is therefore essential.
6. As regards reproduction our rights should include:
 - a) Regulating our own fertility safely and effectively, by conceiving when desired, terminating unwanted pregnancies, and carrying wanted pregnancies to term
 - b) Bearing and raising healthy children with the cooperation of males in the family and society
 - c) Remaining free of disease, disability, fear, pain or death associated with reproduction, the reproductive system and with sexuality.

And now to look at some special areas of concern that we women are bothered about...



Some Special Areas of Concern

Nutrition and Health

Malnutrition is much more common in the girl child than it is the boy. The resulting stunting of growth is itself a health hazard throughout life but more so during pregnancy, when the risk of death during pregnancy is multiplied many times over. Stunting also means the irreversible underdevelopment of the child.

Girls are again at high risk for malnutrition during adolescence! Once again this is a major period of considerable growth and organ formation and the inadequate nutrition leaves the young woman further stunted.

Iron intake of girls is about half of the recommended allowance especially during adolescence and the condition of anemia worsens with further losses due to menstruation.



- In spite of the Mother & Child Health and Anaemia Prophylaxis Programmes, 85% of pregnant women are Anaemic !
- 20% pregnant women are stunted i.e., high-risk mothers with less than 4' 10" making their childbirth difficult.
- 50% pregnant women fail to put on appropriate weight due to
 - * Inadequate Food
 - * Eating last and least;
 - * Double and triple burden;
 - * Unjust sharing of food and work;
 - * Caloric deficit;
 - * Inadequate care and nourishment in the matrimonial home.

Education



Female literacy rates are less than half the rate for rural males! For dalit and adivasis women it is even lower.

Almost 60 per cent of India's non-literate citizens are

women. Not just in literacy - at all levels, whether it is primary school, secondary school or college, women are fewer in number than men. This is an index of discrimination against women. It is also a major factor in the poor health of women and in their inability to resist discrimination. Many social goals including reduced infant mortality or fertility control are closely linked to educational levels of women!

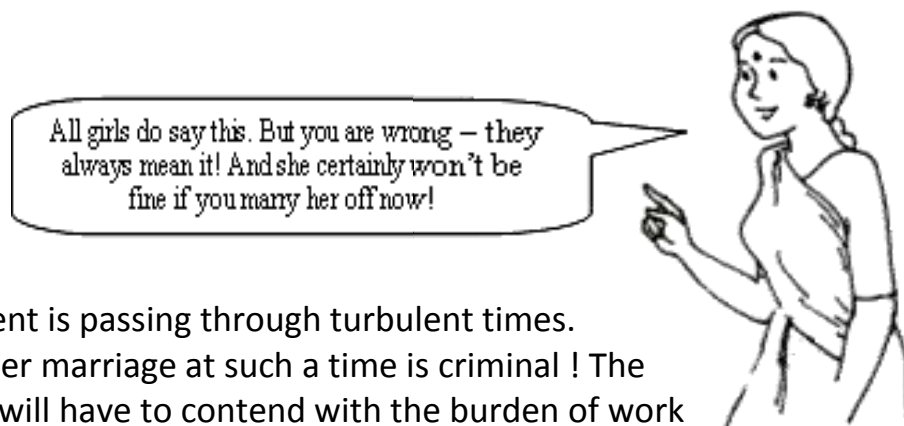
Adolescence & Early Marriage

The onset of puberty is a time of crisis for women.

There are also emotional changes, in the way the adolescent views herself. There are sudden changes in the attitudes of the family and community to her, changes that are often irrational and discriminatory, which she resents and is completely unprepared for. One discriminatory change for example is the way she is restricted from outdoor activity!

My body is undergoing physical changes. I need to know what is happening to me! Why am I being kept in the dark?





An adolescent is passing through turbulent times. Arranging her marriage at such a time is criminal ! The adolescent will have to contend with the burden of work and inferior status in the marital home. She will be have to play a role as wife and mother for which she is physically, mentally and emotionally unprepared. The cost to her health and well being is enormous. Early marriages, pregnancies and motherhood result in acute health risks leading to maternal and child deaths.

Violence



Violence against girls and women is pervasive among all social classes and castes in India, battering them at every stage of life. Violence against women is rooted in the tradition of discrimination that has been going on for centuries.

Rape, sexual harassment, murder, dowry deaths, sati, physical and psychological abuse, female foeticide and infanticide are among the numerous forms of violence against women that are increasingly being reported in India.



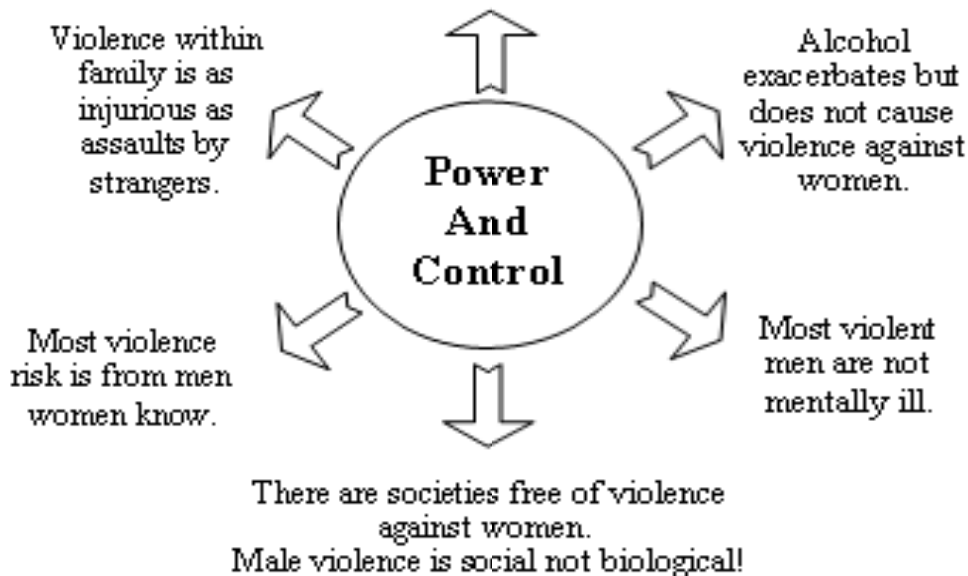
Most violence related injuries are perpetrated by men against women – violence is a gender issue! Gender violence cuts across all socio-economic groups.

Let's try to understand this violence against women...



Violence centers around Power and Control. A man chooses to use violence because through it he can exert his power on the woman and try to control her. He knows he can get away with it.

Emotional & psychological abuse can be as debilitating as physical abuse. Mental torture, Fear of violence, Terror, Depression, Loss of confidence, Effect on children.





Remember, women face violence of different forms all through their lives!

VIOLENCE WOMEN FACE OVER THEIR LIFE CYCLE	
FETOUS	Sex section and foeticide
INTANT	Infanticide and mal nutrition
GIRLHOOD	Socialization into a female Unfair sharing of work and food, sexual abuse, physical and mental violence
ADOLASCENCE	Early and sometimes forced marriage Pregnancy Confusion against unexplained body changes
ADULT WOMEN	Marital rape and wife battering Sexual harassment at workplace Dowry harassment Infertility failure to produce Son Desertion High maternal mortality Medical violence- needless hysterectomy, caesareans Hazardous contraceptive like quinacrine
OLDER WOMEN	Desertation and Neglect- Emotional Security Lack of Financial and social security Misuse of Mental health act

This Gender Based Violence affects our health seriously. Some of us commit suicides, others are murdered. But many more of us are affected in less dramatic but still equally serious ways!

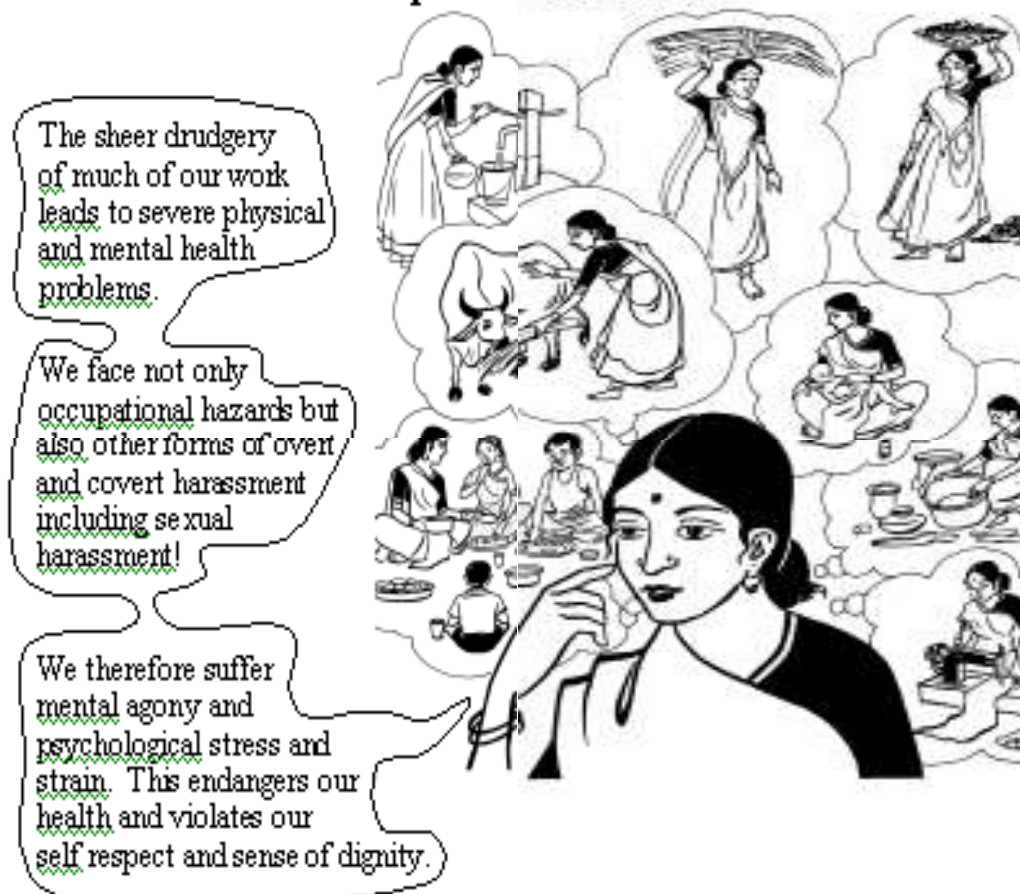


The Physical and Mental Consequences of Violence

PHYSICAL	MENTAL
Sexually Transmitted Diseases (STDs)	Post traumatic Stress Disorder
Pelvic Inflammatory Disease (PID)	Self-neglect & Depression
Unwanted pregnancy & miscarriages	Withdrawal
Chronic pelvic pain	Anxiety, Insecurity
Gynecological Problems	Multiple Personality Disorder
Headache & Asthma	Obsessive Compulsive Disorder
Diarrhea & Irritable Bowel Syndrome	Sexual Dysfunction
Broken bones, head injury, cuts, bruises,	Eating, Drinking Disorders
Rupture of ear drum and jaw dislocation	Suicidal Tendency
Injurious Health Behaviour like Alcohol, Tobacco, Drugs & Sedatives	

In addition, we also suffer the social consequences of such violence.

Occupational hazards



The health of women health care providers



- We women, have been the most important health care givers from times immemorial, tending to our family and our community - both in traditional cultures and in modern times.
- We - as Dais, ANMs, Nurses or Anganwadi workers - continue to provide most of the care, but our contribution is not adequately recognized and often undervalued. The Anganwadi worker for example has an enormous list of work, but very little support and very little as wages (about Rs 400 per month!) The ANM has a better salary, but still very little support.
- We are often subject to harassment on the job. Because we are the junior-most staff and because we are poorly organized we become scape-goats for most failures of the system. Many of us are also sexually harassed and often even raped!
- Just reaching the areas we serve is a problem. The poor status of our work along with the problem of managing our family and our own children demoralizes us. Many of us have marital problems. But the bureaucracy is quite insensitive to these issues and there are no institutional mechanisms handle these problems either.
- Our work will be much easier, even enjoyable, if we have the community's support. Unfortunately, we are required and only allowed to hand down services - we have neither the training nor the permission



to respond to local health priorities. This lack of space for community participation in the health programme design, ensures that we get alienated from the community!

Interventions - The

Notion of Empowerment

Our health will improve sustainably only if we are empowered. Therefore health intervention should go hand in hand with interventions for our empowerment - in fact the health intervention should itself promote empowerment.

No! At least in the short run, it possible to organize health interventions that

increase women's dependence, indebt them further, and legitimize their oppression. Thus a campaign against female feticide or for fertility control could act to threaten and dominate women. We reject such approaches that seek to reinforce domination or domestication of women. On the contrary, we seek approaches that empower women. The empowerment approach essentially *challenges structures, systems and practices that reinforce gender discrimination and helps women to gain access and control over their own bodies and minds and helps women to gain social status and a role in decision-making!*.

But isn't this always the case - that health will promote empowerment?



Empowerment Strategies can be many and should include:

1. Working with the poorest and most oppressed women within a selected geo-political region.
2. Mobilizing, learning from & raising women's consciousness.
3. Creating a separate time and space for women to be together as women, rather than as mere recipients of welfare or development schemes. These forums should enable women to form a cohesive collective.
4. Beginning with women's own experiences and realities: promoting self-recognition and positive self-image, stimulating critical thinking and deepening their understanding of gender and the structures of power
5. Expanding women's horizons by equipping them with the capabilities to access more information, knowledge and skills on their own.
6. Enabling women to identify and prioritize issues that affect their lives for action and to make informed decisions.
7. Enabling women to formulate their own vision of an alternative society, including alternate models of social and economic relations and alternate development theories.
8. Strengthening women's independent and interdependent struggle for change in the material conditions of their existence, in their personal lives and in their treatment in the public sphere.

9. Facilitating the formation of women's mass organisations at local, regional, national and international levels in order to bring about changes in the structures that undermine women's status.



All policies that affect our health should be subjected to review and new policies evolved where there are inadequacies and lacunae at present. In particular we demand that:

1. A National Population Policy should be formulated only after an open & widespread debate with attention to the comments & criticisms already communicated by various concerned groups. The new population policy should adhere to the commitments made at Alma Ata, CEDAW and the Convention on the Rights of the Child, firmly steering clear of all coercive measures and disincentives.
2. The highest priority to be placed on education, health care, food and employment of women and all programs and policies of the state should respect our social, reproductive and economic rights.
3. Suitable legislative and administrative measures to urgently address the following concerns:
 - Increasing privatization of health care and the rise in prices of life-saving drugs.
 - Increasing maternal deaths in abortion related cases.
 - Increasing lack of food, malnutrition, feminization of poverty.
 - Growing illegal use of women for contraceptive research.

- Increasing emphasis on Reproductive health without integrated strategies to tackle social issues of male legal responsibility, sexual violence, issues of values in adolescent reproductive health education, and commodification of women.
- Increasing prostitution of children especially the girl child.



1. Identify in your area, major causes of mortality and morbidity in women and girls and seek women's assessment of women's and communities' need. Also critically analyze the roots of ill health and current trends.
2. Sensitize the public, health department, schools & panchayats about women's social reality & expose the myths that sanctify discrimination - gender stereotypes (like women are women's worst enemies), the role of XY Chromosome in Sex Determination etc.
3. Prioritize the meeting of Basic Needs (Basic Health, Education & Housing) and social security for women within all local planning and developmental work.
4. Familiarize yourself with all govt. welfare & health programmes, Government schemes for girls and women and other opportunities for growth. Disseminate such information to other women.
5. Familiarize your community with health facilities available locally, especially the extensive maternal and childcare services that are available through the primary health center network & the ICDS schemes. Ensure full utilization of existing facilities & build public opinion for expanding such services and improving their quality.
6. Share experiences about using different approaches and strategies and using government and NGOs initiatives. (Like the Sathin Programme,

- Dangar Dais, Total Literacy Campaigns, Mahila Mistris, Anti-arrack movement, Barefoot Handpump mechanics)
7. Understand and Document Traditional Systems, local health practices, local health culture, Traditional System of Medicine, existing health facilities, health situation & referral system.
 8. Prepare an Essential & Rational Health Care Package that provides health education as well as prevention & also easily accessible, affordable and safe essential curative care. Train village health workers to reach such information and skills to poor women. Train health personnel in prevention and rational management of health problems and understanding their roots.
 9. Develop a good Management Information System & register marriages, pregnancies, childbirths, deaths, acute communicable disease outbreaks (malaria, cholera) & collect disease data with gender dimensions (like Suicides, TB and Malaria) in your area.
 10. Help women get their legal/social rights eg. register marriages, ensure joint pattas to home, land, joint guardianship of children, Stree Dhan received at marriage as a norm.
 11. Identify Occupational Health Hazards for women (specially during pregnancy) in different occupations in the region including hazards due to domestic work eg. cooking, smoke.
 12. Initiate Income Generation Programmes. Ensure minimum wages. Equal wages for equal work, maternity benefits etc., and save money and family resources on liquor and inessential drugs.
 13. Develop labour saving devices/technologies/work organization so as to decrease disease and work burden, enhance incomes, cooking fuel alternatives & smokeless chulha, recycling of water, conservation of waste water as well as conservation of rain water.
 14. Organize women workers in the unorganized sector - Sewa has done. Promote organization of dais, midwives, ANMs etc.
 15. Make credit and loans at low cost interest easily available to prevent families falling into clutches of moneylenders. Build women's financial security. The credit cooperative network is one of the most powerful and effective of such interventions.
 16. Provide legal literacy, legal aid and use legal tools to assist women in crisis situations and women facing violence. Develop mechanisms for counselling and providing support to the violence affected.

Chapter. 3

My Family, Myself! *and The Family Planning Programme*



The Genesis of the Indian Family Planning Programme

Hey! What happened to the land reforms, jobs, health, education, water and food for all that you promised during the freedom struggle?



Minister speech

We are indeed making a lot of development gains. But uncontrolled population growth is eating it all away! The poor are breeding so irresponsibly.

How do we stop the poor from breeding?



Let's start a population control programme!



Thus began the Indian family programme policy - one of the earliest and largest family planning programmes in the world. Its budget is equal to the entire health budget of the country. Politically, it has always been a top priority. Yet it has failed. Why?

Naturally it failed. It had to! Because the theory that development is being eaten away by population increase is a false premise to start with.





Without population control
how to reduce poverty?

First let's look at two
issues clearly...



What causes poverty?

1. Concentration of wealth and power in the hands of a few.
2. Economic & Ideological structures which help perpetuate and sustain this power.

**Therefore,
it is Inequality that
causes poverty!**

What causes population increase?

1. Wide spread poverty & lack of economic security! Why? Because to the poor, children are not a liability: they earn! With each mouth comes two hands!
2. Lack of social security – children are the only old age insurance they can afford. Combined with high child mortality rates this means, to be sure of a surviving **male** child, they need to produce several children.
3. Women's lack of control over their bodies – men decide when and how often women should go through the pain of bearing children! Her lack of education contributes to her powerlessness.
4. Unmet contraceptive demand – the poor can't access contraceptives in village even today leading to poor fertility control.

**Therefore, it is Poverty and
Patriarchy that cause
population increase!**

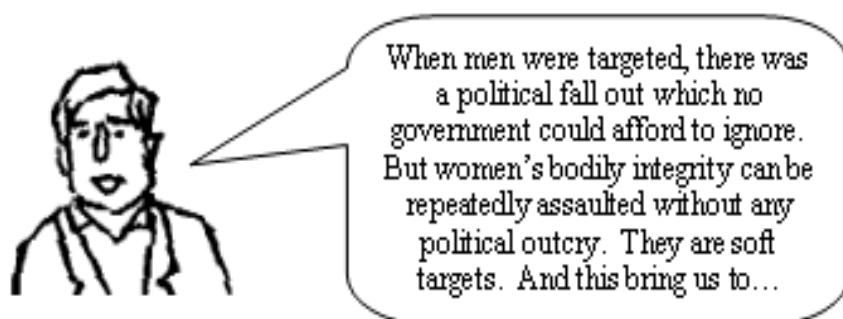
So your understanding that population causes poverty is wrong! It is poverty that causes population increase! As the 1984 Budapest conference said "Development is the best contraceptive!"





How is the Indian Family Planning Programme anti-poor ?

1. By functioning as an ideology of oppression - making the poor feel individual guilt & responsibility for their socially determined condition, thereby preventing them from organizing and demanding a better deal! But focusing on population as the reason for poverty, the family planning programme diverts attention away from inequality and its inaction on this front.
2. It is also anti-poor because of the way the government coerces unethical and dangerous Family Planning methods on the poor and particularly on poor women.



How the Family Planning Programme is anti-women!

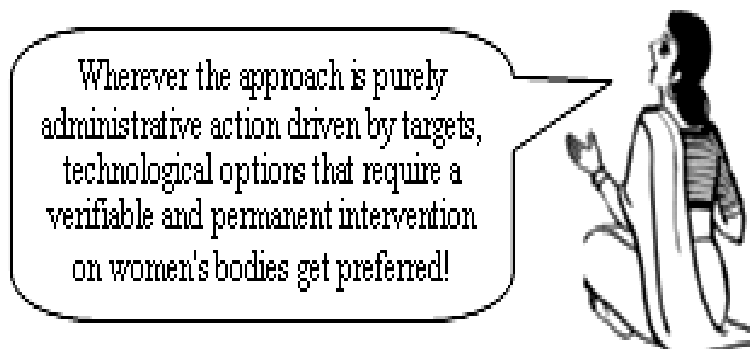
The basic approach to the family planning was to get as many couples as possible to accept contraception, whether forcible or otherwise.

Targets were distributed to the health department functionaries, especially the ANMs (the multipurpose health worker) and it was made clear that of all the various primary health care programmes this was the most important. She could lose her job if she did not reach her targets.

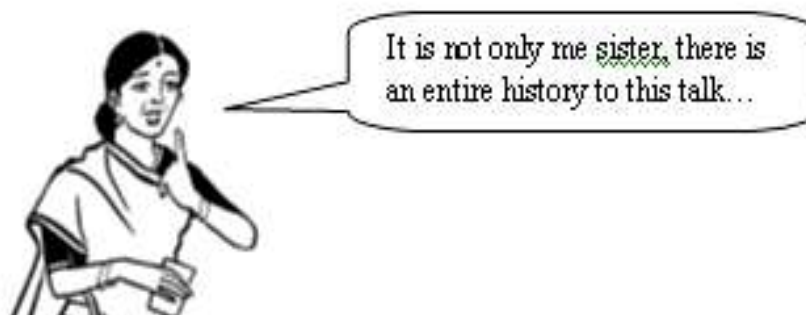
Targets were also distributed to everyone possible - from the village patwari and schoolteacher, to all government functionaries.

History of Family Planning in India...

In the 1960s, the targets were for IUDs. For some time in between vasectomies was the focus. But, during the emergency period this was done so ruthlessly and it backfired so badly that for all purposes it has been off the menu ever since! Then came the Tubectomy drives, and now we are in the era of Laproscopic Tubectomies. In between, there were also some efforts at popularizing oral pills, and lately, a stress on implantable/ injectable contraceptives.



Sterilization as an irreversible & permanent option was seen as preferable, though insertion of IUDs was seen as the most preferred non-permanent option. The experience with all these drives was that generally targets were fulfilled (on paper) but only transiently. And the important point is that, birth rates did not show corresponding decline!



Almost since the beginning of this century, women's movements have articulated the need for fertility control as a means for enabling women to decide on her own fertility. Here fertility control is seen as part of the spectrum of women's rights. Nor does this notion of enabling women relate only to choosing family size. It relates to a whole number of issues regarding

reproduction and reproductive and sexual health rights. These include the right to:

1. Regulate their own fertility safely and effectively, by conceiving when desired, terminating unwanted pregnancies, and carrying wanted pregnancies to term.
2. Bear and raise healthy children.
3. Remain free of disease, disability, fear, pain, violence or death associated with reproduction, the reproductive system and with sexuality.

Education and empowerment enables us to make choices, to take decisions. Enabled thus, no woman would willingly choose more than 2-3 children!

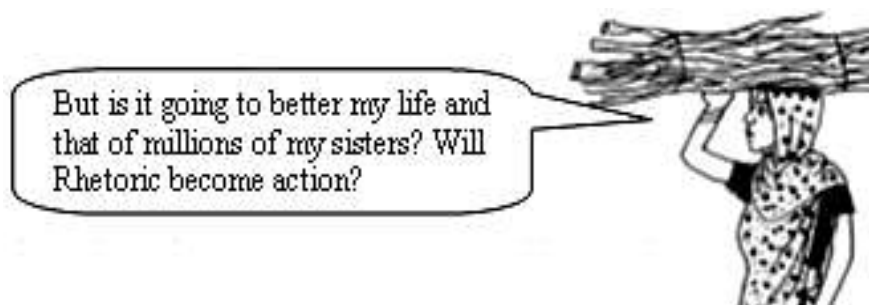
Family Planning - The Right to Safe Contraception!

The right and ability to have the number of children we want, at a time when we want them is Family Planning. This is our fundamental right! Providing for universal access to safe contraception is essential state responsibility.

Policy Change!

Many features of these changes in the last few years are praise worthy.

1. Policy has moved away from a target driven approach.
2. Importance of addressing all the issues concerning reproductive health care is recognized, at least on paper.



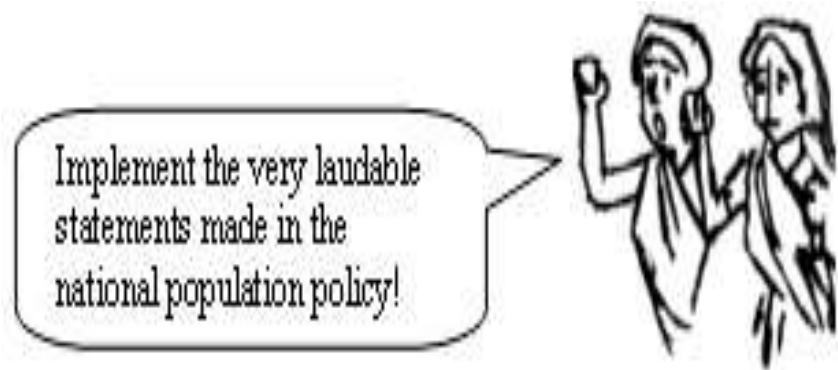
Looking closer there are some remaining problems and some new ones with current policy directions:

1. The entire approach is still contraceptive centered. The shift from the assumption that contraceptives have to be thrust on unwilling women to an understanding of unmet demand is welcome. But the failure to recognize even on paper the other determinants of population, especially the relationship with poverty and underdevelopment is not.
2. Equating Reproductive Health to just maternal care and fertility control is far too simplistic. Leaving out or inadequately addressing other major determinants like sexuality, cultural values, infertility services or reproductive tract infections, is not acceptable.
3. Provider controlled, long acting, invasive, hormonal methods - like Norplant and injectables which are hazardous for women, are sought to be introduced.
4. There is an assumption that privatization of certain services will provide a better outreach and make it more consumer friendly. For this a number of incentives to private sector are proposed -incentives for the private sector to open health enterprises in remote areas, use of public facilities, more space in production of contraception, food supplements, more profits from IEC (publicity related) work etc. The introduction of Quinacrine for sterilization by the private sector before women's groups forced its ban is an example of this.
5. Though targets as such are removed, the plan is to allow such targets to be set at the local level through a planning process. It is unlikely that when other dimensions of health are not addressed, fertility control planning alone will help. Moreover, a number of disincentives like insisting on a two-child norm for holding elected office in panchayats are being brought in, in the hope that they would be more effective. A move to link ration cards to a two-child norm in Delhi was fought of but utmost vigilance would be needed to keep newer variants of targets from gaining hold.
6. There is a marked shift to the use of loans from international agencies for programmes of reproductive health. There are three problems with this:
 - a. It indebts us further & as time passes loan repayments on health loans will become more and more of a burden.
 - b. It gives donor agencies almost unlimited control over all aspects of the programme, even if the loan amount is only a small part of what we spend from our own resources.
 - c. A large part of these loans flow back to the developed world as profits. The RCH loan of 308.8 million, for eg., allocates 16% (\$47.6 million) for surveys & payment to consultants. A good part will be foreign consultations. By insisting on global tenders for

supplying materials & by encouraging programmes based on marketable commodities, international big business is able to enter in a big way.

Policy Changes and Peoples Initiatives

The main thrust of people's action:



This policy statement should be seen as part of the outcome of over 50 years of work by concerned academicians, women's movements and NGOs in health action to bring about a better understanding of the population issue. Even in the last stages, it was good advocacy that prevented something like the two-child norm for local body's elections from getting into the policy statement. The weaknesses of the current policy (discussed above) needs be corrected by further advocacy, but it is far more important to ensure that the broad thrust of its statements are reflected in financial commitments, in the design of schemes, and at the level of implementation.

The administration has a tendency to quote and use that segment of the policy statement that suits their real goals. People's organisations too can use policy documents in a similar manner as part of advocacy efforts. In a sense, the policy document is the result of an implicit negotiation between different parties, and pressing to implement it reflects an awareness that only if there is such pressure will the agreed upon negotiation be adhered to!

Since governments are likely to keep their commitments regarding contraception provision but more likely to forget all other dimensions of reproductive health care and women's health issues as well as the inter-sectoral linkages, the thrust of the peoples campaign lies in these areas.

India's population policies are largely influenced by Western understanding of the need to control populations of the third world. Indeed, it would appear that global resources are threatened by such growth and hence imposing control is legitimate and even desirable. This argument is fallacious. First world countries are more of a threat to global resources, due to their much higher levels of consumption. It is estimated that the each child born in the U.S. consumes as much energy as 3 Japanese, 6 Mexicans, 12 Chinese, 33 Indians or 147 Bangladeshis! The total energy consumed by the U.S. is 25 times the Indian consumption despite the fact that the U.S. population is only one fourth of ours. If all the countries were to move towards catching up to the U.S. level of growth the global resources would vanish in no time! It follows that the urgent agenda, much more important than controlling populations, is curbing the luxurious and wasteful consumption of the West!

Chapter. 4

Her Name is Today

*We are guilty of many errors and many faults,
But our worst crime is abandoning the children,
Neglecting the fountain of life.
Many of the things we need can wait.
The child cannot.
Right now is the time his bones are being formed,
His blood is being made,
And his senses are being developed.
To him we cannot answer 'Tomorrow'.
His name is 'Today'.
- Gabriela Mistral, of Chile*



Out of 1000 children who are born like me - 330 have low birth weight, 71 will die before their first birthday and another 37 before they five.

I am one of the lucky few! Only 51% of babies in India are exclusively breast-fed for the first 3 months.



I am also lucky my dai was trained and told me to breast feed my baby. Only 34% of births are attended by trained health personnel.



53% of under-fives in India are under weight, out of which 21% are severely under weight.

- Infant and child mortality rates are higher amongst Dalits.
- Preschool education is still inadequate in spite of the ICDS scheme
- Elementary school education is far from becoming universal
- In the 6-14 age group, there are 3 to 4 Crore working children!
- For over 1 Crore out-of-school children in the 6-14 age group, health issues are often those of survival in working environments that are hazardous, harsh and completely unacceptable.
- Growing economic disparities, migration, consumerism, breakdown of family support systems and changing values are increasingly making prostitution and sexual abuse of **children a major health issue.**

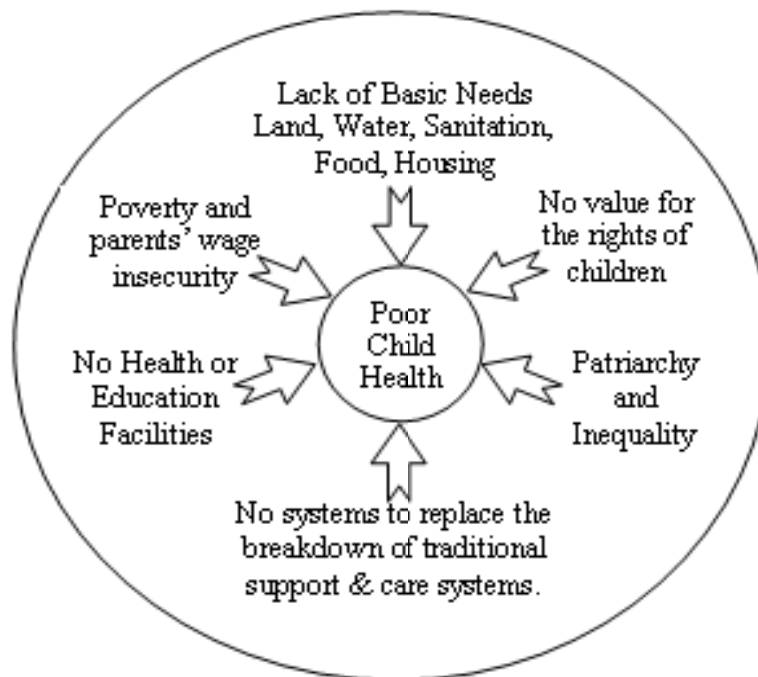
The Challenges



Our health cannot be separated from the socio-economic and political situation of our families and the societies in which they live.

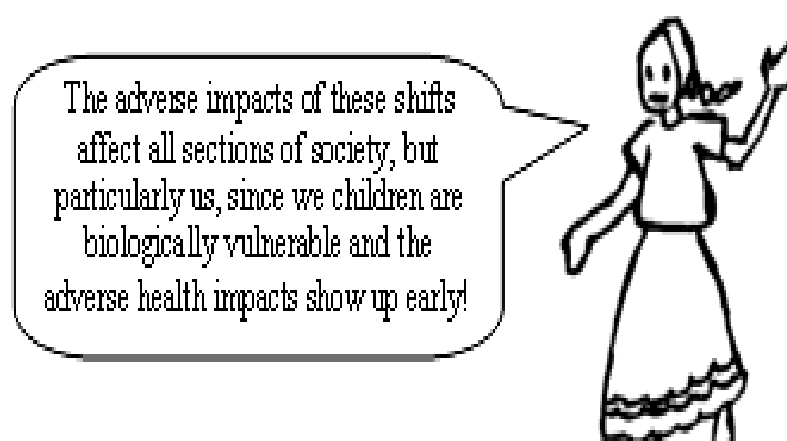
Therefore child health in contemporary India must be seen in the context of the existing class, caste and gender inequities and the effect of current policies upon these prevailing inequities.

The Basic Issues in Child Health



The last decade has seen the new economic policies leading to fundamental changes in the employer-employee relationship and causing shifts such as:

- Women workers from organized to unorganized sector
- Erosion of social security base of working women
- Lack of day care services
- Greater privatization & increasing costs of health care & educational services



Aware of this, the votaries of the new economic paradigm are trying to make some effort at lowest possible costs to contain the inevitable negative changes in infant and child mortality rates!



Well targeted true, but also very limited!

Though some decline in child mortality is gained by some of these measures this is far from adequate, and ill sustained. To the children suffering from ill health there is no relief. In many countries infant mortality has actually gone up after structural adjustment!



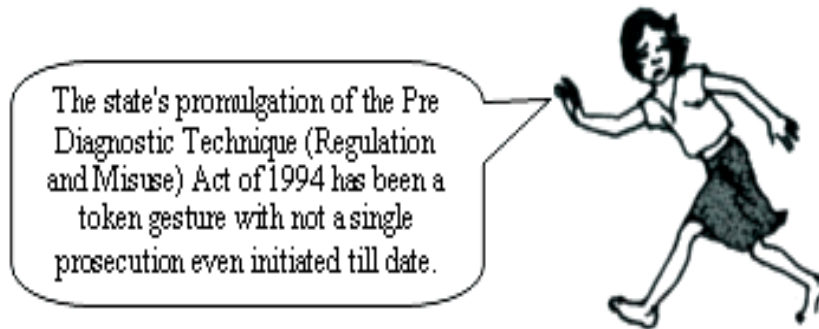
Issues of Concern

Female Foeticide and Infanticide

In all parts of the country, we are discriminated against, but in some parts we are killed as soon as we are born, and of late even before we are born. And this obnoxious practice (particularly feticide) is fast becoming very wide spread because of the rapid spread of prenatal sex determination technologies.

Both forms of murder are no doubt due to the male preference of a patriarchal society but the problem is exacerbated in the modern

technological context and in the context of how pressures to limit the number of children are read



Further the collusion of a highly educated affluent and unethical medical community needs be noted. The professional and regulatory bodies of the professionals have been completely silent about their role in this illegal practice!

There is a danger that as coercive measures to impose a two child norm continue, female feticide will worsen. Despite the international commitment to a target free, non-coercive approach, widespread propaganda towards a two-child norm along with new forms of penalization are in place!

And now they are coming with even harsher ideas - Ineligibility for loans, increments & ration cards! These laws discriminate against the poor & against women & in the prevailing environment of male preference they will exacerbate feticide trends.

Only a planned combination of legal action (especially against erring professionals), and considerable civic action to sensitize professionals & the people can curb this practice.

Food Security and Child Malnutrition

Recent trends in agriculture threatens the food security of the underprivileged. Even small farmers are growing cash crops and export oriented crops - but they do not reliably bring in cash!

The continuing malnutrition of the Indian child is not just a health problem - It is a violation of the basic rights of the child! When compared to level of income, India has higher levels of malnutrition than any country in the world save Bangladesh!

The worsening working conditions is a result of growing unorganized nature of women's work - a direct result of SAP and globalization!

Equally important by decreasing the time the mother has for the child and the consequent worse quality of childcare, there is a direct contribution to malnutrition. In most work places there is no facility for childcare where the woman may breast-feed her child. Even where laws such as the Construction Worker's Act or Maternity Benefits Act are applicable, crèches do not exist. Maternity leave or other benefits are almost non-existent in most jobs of the unorganized sector.

In this situation, often I and girls like me end up caring for the baby and the bottle is the only convenient option for us!

The consequent risks of diarrhoea, malnutrition and death are well documented.

Cultural factors, especially relating to weaning foods & weaning practices also contribute in a major way to malnutrition. The market has a major role in misinforming the poor mother and leading her into costlier less effective breast milk & weaning food substitutes. While packaged formula foods can no longer be advertised, the market of packaged formula feeds is increasing and there is no continuing nutrition education of parents.

We girls are particularly vulnerable to malnutrition due to general discrimination in terms of food allocation within the family, additional responsibilities, and later and lesser access to medical treatment.

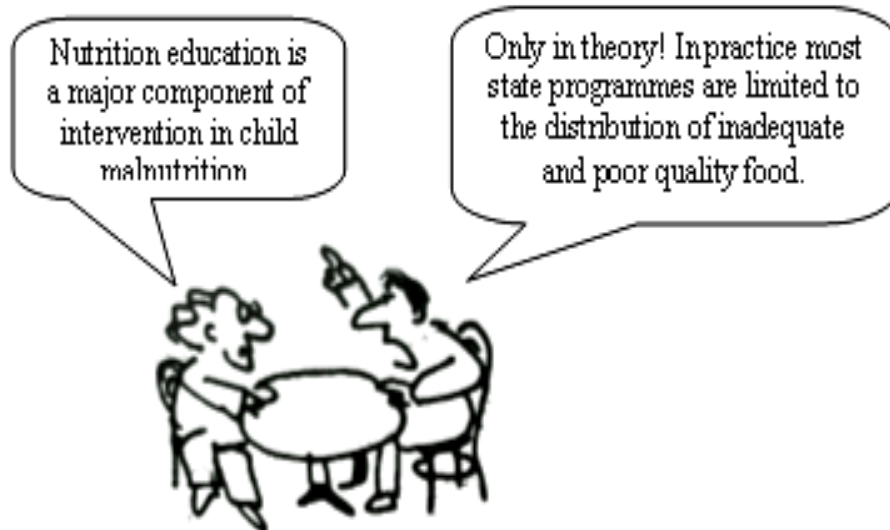
In addition, as we grow older, proneness to anemia due to menstruation, an inadequate appreciation of adolescents food requirements, and early marriages and early motherhood continue our chronic malnutrition and poor health.

Deficiency of Micro-Nutrients

Recently, much research has been done on the role of micronutrient deficiencies in the health of children. It cannot be stated too emphatically that these deficiencies would not occur if children got enough food to eat and that no amount of chemical supplementation can compensate for lack of food. However the pharmaceutical industry (read MNCs) flourishes by using this kind of research and propaganda to flood the market with various kinds of vitamin and mineral tonics. The poor trying to somehow give their children the best cling to these tonics and get cheated of their money further. Meanwhile

relevant government programmes like vitamin A prophylaxis and anemia prophylaxis programmes flounder due to recurrent unavailability of drugs, poor public awareness, and the general problems that beset the government health systems.

Supplementary Feeding programmes and Early Childhood Care



The best example of this is the ICDS: It is the only substantive programme being run for children under six and has the commendable objective of facilitating the overall development of the very young child in a comprehensive and integrated manner.



And that is at best distribution of food. Not surprisingly, where there is no community pressure, Anganwadis are largely non functional!

There are a number of concerns regarding the food supply in these schemes. Corruption and leakages is one concern. Quality is another major concern. One more recent concern is the use of American corn soya blend and similar imported foods, which may be genetically engineered. The principle should be to supply fresh locally grown, locally processed, culturally acceptable food for children.

India has 100 million children below 6 years of age. Of these, 60 million below the poverty line & are malnourished. The ICDS, even on paper, reaches only 22 million of these!

With most women being working mothers, universal day care facilities and social security for caring for children is a minimum social obligation. The quality of such care should go beyond supplementary feeding to early childhood education. Preschool education, but of a sort where the young child does not have a load of school books and is not under pressure to compete and excel, where it has opportunity to play, enjoy and have peer company should be the goal. Unfortunately, this aspect has been sidelined and removed from the purview of education in the 83rd amendment bill, which does not augur well for child health.

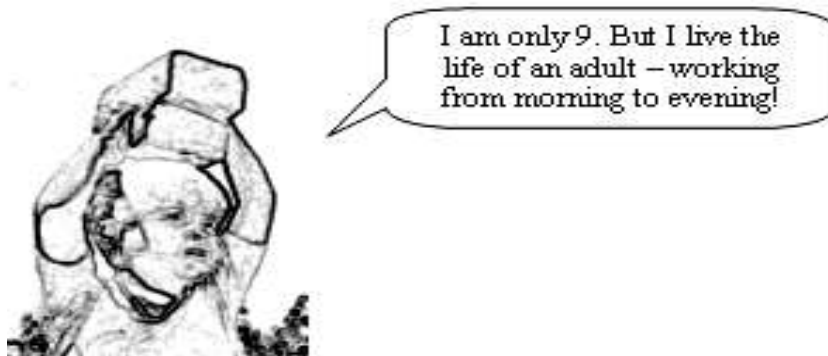
Childhood Diseases

Malnutrition contributes greatly to contracting these diseases and dying from them. Prompt locally available care, based on trained community volunteers can reduce suffering and deaths from these common problems, but still in most villages across the country such first contact care is far from achieved.

The control of immunization preventable diseases is a significant advance, but not if it is pushed as a substitute for proper access to child health care. The popular perception of immunization injection as an all purpose saviour from ill health is such a misunderstanding. In practice in most PHCs this is the only dimension of child health that ever gets noticed. Even in this, diseases like measles are poorly covered, the center stage having become occupied by the pulse polio campaign.

Finally apart from all these, the lack of safe drinking water, sanitation, lack of good quality health care services, lack of information to parents, teachers and child care providers, inappropriate management by health workers and doctors (unnecessary use of antibiotics) and rising cost of medicine continue to contribute to the increasing vulnerability and ill health of the young child.

The Working Child



This invariably damages their growth and development and violates their basic rights. Thus child labor of any description is hazardous and this should include the labour put in by children in their own poor households at the cost of their own health and education.

Our main health problem is Survival!

Especially true for children in dangerous occupation like firework making, rag picking etc. The other important problem is the constant drudgery and strain of their work. The children who survive are often scarred for life by hampered growth, occupational disease and having remained unschooled while their peers move ahead. These are handicaps that rob them of their full potential and leave them with handicaps that can almost never be made up.

Bonded child labour is more in some industries like beedis, brick-kilns, carpet making and in certain areas.

Universal free and compulsory elementary education, employment for all adults and the complete eradication of child labour are the only adequate remedy for the health of these children. Implementation of a comprehensive child rights code that addresses the problem of child labour as a human rights issue is an urgent necessity.

Other emerging concerns

In a situation of growing economic disparities, migration, consumerism, breakdown of family support systems and changing values, the child is under a new set of stresses and risks to physical and mental health.



This is more so with the most vulnerable amongst us - street children & the children within remand institutions. Asia has now become the largest market for the lucrative trade of child abuse, helped by a situation where foreign exchange earnings (which unregulated tourism brings in) is the societal goal.

The growth of the AIDS/STD problem is another emerging concern. Current approaches to AIDS control do little to examine the problem within a comprehensive understanding of sexual relationships.



And mind you! Not just for girls - boys need it as much!

Unfortunately this is not yet on the agenda. Rather, current AIDS control messages, seldom question aggressive and abusive sexual behaviour, subtly reinforcing the view that one could be safe from transmission without such changes in current sexual norms.

Policy Recommendations

Interventions and responses to improve child health should include the following:

1. 'Two Child Norm' policies need to be scrapped immediately and opposed vigorously.
2. Vigorous public campaign against female foeticide and infanticide.
3. Ensuring basic system of care to facilitate breast feeding of children by working women
 - a. In the short term Maternity leave to be extended to 6 months and Maternity Benefits Act to be applicable to unorganized sector and establishment of creches at worksites should be promote
 - b. In the long term social security measures to enable wage security for period of exclusive breast feeding.
4. All supplementary feeding programmes for children to use locally produced, freshly prepared, culturally acceptable nutritious food.
5. Total eradication of child labour with the strategy of universal, compulsory and free elementary education.
6. Strict regulation of preschool education and schools with strict enforcement of school health programmes including counselling services for children and parents.
7. Comprehensive and overarching Child Rights Code.
8. Greater budgetary allocation for childcare services (at least 1% of GDP), ICDS (15 rupees per child per day) and education (over 10% of GDP).
9. Vertical schemes like RCH to be scrapped with strengthening of overall primary health care and its system of delivery. Special focus on maternity and child care through the primary health care system.
10. Since the Integrated Child Development Service is the only social security scheme that has the potential to reach the poor working mother and the vulnerable young child a complete overhaul to improve the quality and outreach of the service is a practical imperative.

Recommendations on ICDS

- a. Upgrade facilities and infrastructure
- b. Issue guidelines for locating Aanganwadis and setting their timings to correspond to needs of target group
- c. Redesign outreach to under-threes and pregnant and lactating women & make provision of Daycare centers & Aanganwadis.
- d. Revise nutrition programme - distribution system & type of food.
- e. Increase emphasis on neglected components of ICDS package, particularly early childhood education.
- f. Initiate Convergence of Services at both planning and implementation levels.
- g. Revise Training & Evaluation to include critical missing components.
- h. Revamp Status, remuneration and conditions of work and number of the Anganwadi Workers keeping in mind their work load and required child - adult ratio.
- i. Build in flexibility in management and design of ICDS and include ground principle of partnership between Government, NGOs and People groups
- j. Decentralize to Panchayat Raj Institutions with continuing responsibility for finances and service conditions.
- k. Increase overall allocation for Early Childhood Care and develop strategies for alternate source of funding.

Universalize ICDS and coincide it with removal of identified shortcomings!

People's Initiatives

1. Help organize the local community and women to identify problems of children locally and act collectively to improve their lot. Such people's initiatives should include at least ensuring that every child goes to school and is supported to learn adequately
2. Assist families to prevent malnutrition and disease in their children by appropriate health education and better utilization of existing services
3. Strengthen day care services for children by community support
4. Assist Panchayats in taking care and entirely taking over all aspects of child support

Chapter.5

And they call us children!

I polish shoes at the signal near your house. In every town and city, live a lot of children like me. Robbed of our childhood and adult protection,



we have to negotiate our precarious existence in an adult world of crime, misery, abuse and exploitation.

For me and 40 million street and working children like me, survival is the name of the game!

I am a child on the street. I work here as a ragpicker. But I have a family and a home.



I am a child of the street. I have neither family nor home. But I have a lot of friends and we all live here on the street.

We children of the street have run away from oppressive and traumatic homes. We have seen it all - conflicts, anguish and abuse much beyond our tolerance level.



There are also children on the streets who have lost their parents or have been abandoned by them.



Most street children are deviant and delinquent. Little rowdies!



No, we are not!
We are often more gifted than other children. We had the spirit and strength to rebel against our oppressive condition. Most other children lack this courage.

Studies show that not more than 6% show delinquent behaviour.

Most of us (more boys than girls) belong to the age group of 7 to 18 years. We come to towns & cities from various parts of the country, with a wide range of religious, cultural and linguistic backgrounds. But being smart, we quickly learn to communicate in the principal languages spoken in our area!



When I first came to this city, I didn't know what to do and where to go. It was frightening. But then I found other boys like me and joined their gang. The gang is now my family - we share what we have and protect each other.

Problems We Face...

Deprived of adult protection, guidance, love and support, we are abused by all and sundry. Almost all of us have been beaten by the police. Both boys and girls amongst us are easy prey for sexual assault and child prostitution.

Living without shelter, sleeping under bridges, on pavements, railway stations and in cement pipes - affects us psychologically. We develop a sense of inferiority and insecurity. We also learn not to trust adults. Our life is governed by a 'here & now' attitude. We do dream about our future - but we also know that they will remain dreams!

Because we look dirty, we are not allowed to use public parks. We never get to play like other 'normal' kids.

Unable to expend our surplus energy Through play, our life becomes centered around films and gambling. Many of us become easy prey to drugs and die a slow death, unnoticed and unlamented.

Of course there is no question of schools and health facilities for us! Even those of us who know to read, slowly lapse into illiteracy.

We have to earn our living and the jobs that we get are of the worst sort like rag-picking- dirty, unhygienic and hazardous. We only get jobs no one else will do.

Our irregular, unhygienic and inadequate intake of food makes us malnourished and susceptible to a variety of illnesses - infectious diseases, gastrointestinal problems, STDs, scabies, fever and jaundice.



By the way, the life of a street girl is a lot more difficult! Our freedom is snatched away by pimps and molesters. Often we end up as prostitutes.

Interventions

Most government and police officials see street children as delinquents and anti-social elements who need reforming. Therefore their approach has been to 'rehabilitate' the child - focusing on correctional and remedial institutions.

Trying to confine us to institutions is futile. Remember, we rebelled and escaped from houses because they were crushing our spirit.

Many NGOs have developed excellent models from which important lessons can be drawn. Some NGOs have used a totally unstructured approach - meeting us at street corners, railway platforms on specified days and times providing only guidance and some minimal equipment for functional literacy and indoor recreation. There are other organizations which offer semi-institutionalized support - which invite to stay in a house with house-parents on a completely voluntary basis. Then there are organizations that have helped us form cooperatives and encouraged us to save for our future.

Below we list a charter of demands! Implement them and give us a World where We Matter!

Street Children's Charter of Demands

1. Shelter: This is our first most basic physical need.

- a. Provide professionally managed night-shelters, preferably run by NGO's, with lockers, bathing, toilet & recreational facilities. Access to such shelters should be voluntary.

2. Protection: This is our second basic survival need.

- a. Sensitize police officials at all levels about our rights
- b. Locate trained volunteer social workers in police stations or clusters of police stations located in areas where we are in large numbers to intercede, intervene & follow-up on our behalf.
- c. Encourage senior police officials to provide us with identity cards. This can help prevent police harassment.
- d. Ensure early and strict police action when we complain of physical and sexual abuse.
- e. Ensure that we - especially the large majority of us without criminal records - are not committed to correctional institutions against our will!
- f. Special and readily accessible small savings thrift and banking programmes

3. Educational and Vocational Training

- a. Organize evening non-formal education classes, selecting motivated & trained teachers & an appropriate pedagogy.
- b. But don't condemn us to NFE alone - if you provide bridge facilities to assist our transition to formal schools, many of us will happily enter/re-enter the regular school.
- c. Those of us who dropped out but want to complete high school, should be provided with the open school option.

- d. Organize vocational training in carefully selected vocations with high employment potential for the older amongst us.
- e. Advocate for our employment and assist us in self-employment (credit, subsidy, skills, marketing, etc.) through IRDP, NRY, self-employment programmes for educated etc.

4. Health Care:

- a. Mobile health teams or satellite health clinics should regularly visit specified points at specified times in areas where we live and work in large numbers.
- b. Counseling and emotional support services for our mental health needs through professionals or trained volunteers.
- c. Provide us with a Mid-day meal or other such supplementary nutrition programmes. Identify and help those of us who are dependent on drugs, ensure intensive counseling, detoxification and emotional support services to prevent recurrence.

5. Recreation:

- a. Encourage Citizens' groups / youth clubs etc. to organize regular and structured recreational facilities like picnics, games, film-shows and camps for us.

Chapter.6

We are the Differently Abled !

Happy be they who see and love me as I am, as I alone am, and not as some would want me to be.

*Argentinian National Association
for the Promotion of Disabled People*



What is Disability?

Disability is when a loss or reduction in any physiological function results in a partial or total inability to perform any bodily or mental functions in a manner or within the range considered normal for a human being.

There is a critical problem with this definition. The definition hinges on the word 'normal' !

Blind people often develop the ability to remember the positions of objects. This helps them walk around objects without colliding. During the day, a 'normal' person may have an advantage over the blind person. But at night, the blind person has the advantage.

Why then is only the blind person disabled? Isn't the 'normal' person disabled with respect to the blind person at night?

Every human being is good at some things and bad at others. 'Disability' is more the result of an unfair society valuing certain abilities over others and not an intrinsic lack of ability.





Hey! That's going too far. How can you say that a blind person is the same as other nor... err... ordinary people? Also doesn't that mean they don't need any special help – then why this chapter?



I never said that a blind person does not need special help! I am just pointing out that this special help is needed because today's society is unfair to the blind. Their needing help is not 'natural' nor are they inferior to 'other normal' people!

The struggle for a better life for the disabled is a part of a larger effort to create a world where more value is placed on being human than on being 'normal' - a world where war and poverty and despair no longer disable the children of today, who are leaders of tomorrow. - *David Werner*

Did you note the two important points David is making?



1. When we ask for a better life for us, the disabled, we are not asking for pity - we are asking for equality, fairness and only what is rightfully due to us! And by doing this we are also changing the way society is structured.
2. Disability is not an individual problem - it is the

result of society's actions and therefore society is responsible for all disability!



But that's nonsense!
How can you hold society
responsible for your blindness?
You may ask society's help, but
you can't hold the entire society
responsible for your state!



I became blind in my childhood. Because of
poor nutrition and particularly vitamin A
deficiency. There are 9 million blind
people like me in India – and 90% of the
blindness could have been prevented. Since
I was born in a poor family, in a rural area, I could not get treated.
Moreover it was my family's poverty that led to my poor nutrition. I
therefore quite rightly hold the society which allows so much poverty
and inequality to exist responsible for my blindness!

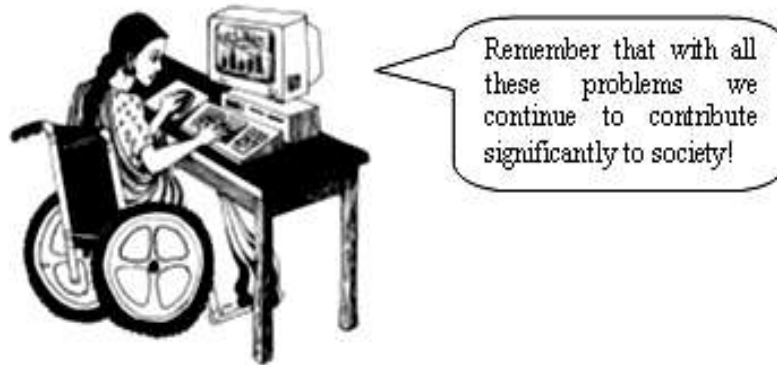


I was afflicted by polio and I agree with her!
There is another example of how society is
responsible for disabilities. In Punjab, as
part of the Green Revolution, the state
supported the purchase of threshing
machines by a large number of well-to-do
farmers. These machines had little safety
regulations in place. A lot of poor landless
labourers who worked these machines lost
their limbs. Who is responsible for this loss?
The individuals? Definitely not! A society,
unwilling to make the rich pay for safety
provisions, has to bear the responsibility!

Similar is the case with factories, which pollute the environment leading to a lot of disabilities. Or with rich farmers who use up a lot of water for irrigation leaving only contaminated drinking water available to the poor. Or with wars or crime. A world with so much inequality and so little concern for the right of the poor, and marginalized is to blame!

Our Special Problems

- Society treats us with ignorance, prejudice, revulsion & rejection.
- Economic, social, architectural, educational, legal, transport, cultural, health and other barriers hamper the achievement of our full potential.
- We suffer humiliation, segregation and indignity and therefore from low self-esteem.
- As children, we are excluded from school, play, marriage and employment.
- There is a lack of facilities for diagnosis, treatment, education and rehabilitation, except in few big urban centers.
- Problems are compounded for us in socially discriminated categories of gender, class, caste, minorities etc.



We Demand A World Where We Matter!

- Adherence to national commitment to rights, full participation and empowerment of persons with disabilities as enshrined in the Persons with Disabilities Act, 1995.
- Recognition of the rights and potential of disabled to lead fulfilled, productive lives.
- Concentration on abilities, not inabilities of disabled.
- Not charity, but assistance for dignity and self-reliance
- Detailed house-to-house survey, also opportunity for community education regarding attitudes to disabled.
- Mass education campaign as in Total Literacy Campaigns
- Mobilization and recruitment of voluntary disabled workers in each village
- Training of disabled workers in attitudes and skills for therapy and rehabilitation
- Establishment of village level rehabilitation centers and District Resource Centers

- Resist segregation of disabled in specialized institutions in favour of CBR (Community Based Rehabilitation)
- Specialized institutions such as special schools, residential care centers and sheltered workshops required as resource centers and for the profoundly disabled
- Detailed examination of each disabled person by specialists to identify potentials and required interventions
- Developing low-cost aids and appliances utilizing indigenous materials and local artisan skills
- Organizing medical, including surgical and physiotherapy, interventions by building local competencies
- Supporting formations of self-help groups of disabled persons and their families
- Organizing group care in communities of aging disabled lacking family support
- Special employment exchanges and transport facilities
- Ensuring education of all disabled children, preferably in integrated schools
- Vocational rehabilitation through skills development and active advocacy with potential employers
- Ensuring, as an article of faith, fulfillment of reservations for disabled
- Ensuring access to public places

Respect, not Pity
Rights, not Charity
Equality, not
Dependence
Participation, not
Segregation
- Ali Baquer for VHAI

Chapter.7

The Uncared Age

Growing old gracefully was an old tradition – a tradition which is fast disappearing!



Many young couples shower a lot of attention, love and money on their children - while at the same time neglecting or abusing their parents. They feel that their children will reciprocate their affection. What they don't realize is that their children grow up learning from their parents, how exactly they should treat them later in life!

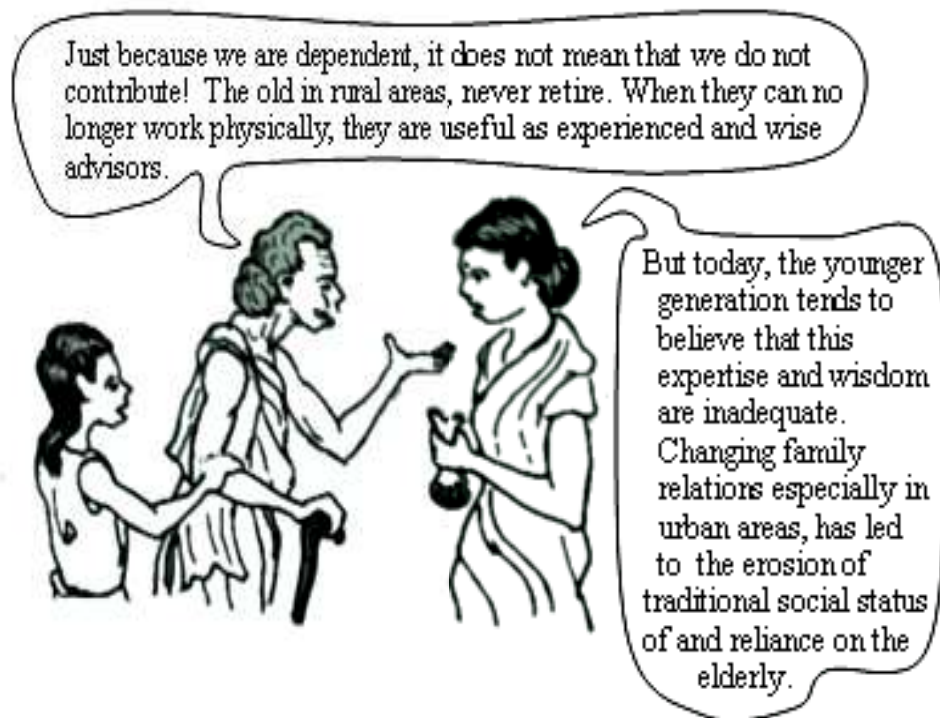
- Selvi, TNSF activist from Ramanathapuram



The society we live in has always been changing. But the speed with which values and cultures have changed across the globe during the last 50 years and particularly in the last twenty years has been unmatched in history. Today's problems of aging are a result of these rapid changes.

What changes and what problems?

Because life spans are lengthening, 60 + age-group growing at faster rate (38 per cent) than rest of population (19 per cent) leading to high dependency ratio!



These factors lead to:

- i. High economic dependence of the elderly (33 per cent in rural and 37 per cent in urban areas)
- ii. Loneliness and lack of emotional support
- iii. Vulnerable to geriatric illnesses, causes high physical dependence
- iv. Loss of self-esteem because of lack of socially and economically productive activities for the elderly.
- v. Problems sometimes compounded by social, cultural practices and gender bias eg., widows of Varanasi.

What is to be done?

1. Economic Security and Self-reliance:

a. For Pensioners:

- I. For retiring government functionaries, regularly monitor timely processing of pension claims; paper-work should commence two years before retirement, special camps may be organised from time to time, latest final disposal should be within six month of retirement
- II. Ensure single-window payment with simple procedures for pension disbursement; involve citizens' groups and local bodies to control corruption in disbursement

b. For non-pensioners:

- I. Organize drive to cover all eligible elderly, specially the destitute with social security pension
- II. Monitor & ensure timely payment of social security pensions

2. Health Care Facilities:

- a. Motivate citizens or senior citizens themselves to establish Senior Citizens' Clubs to provide opportunities for recreation, companionship, gossip, reading, periodicals, indoor games etc.; assist with space, financial and material assistance etc.
- b. Organize systematic treatment of common disabling geriatric problems, e.g., diagnostic and treatment camps for cataract, hearing, dentistry, arthritis etc.

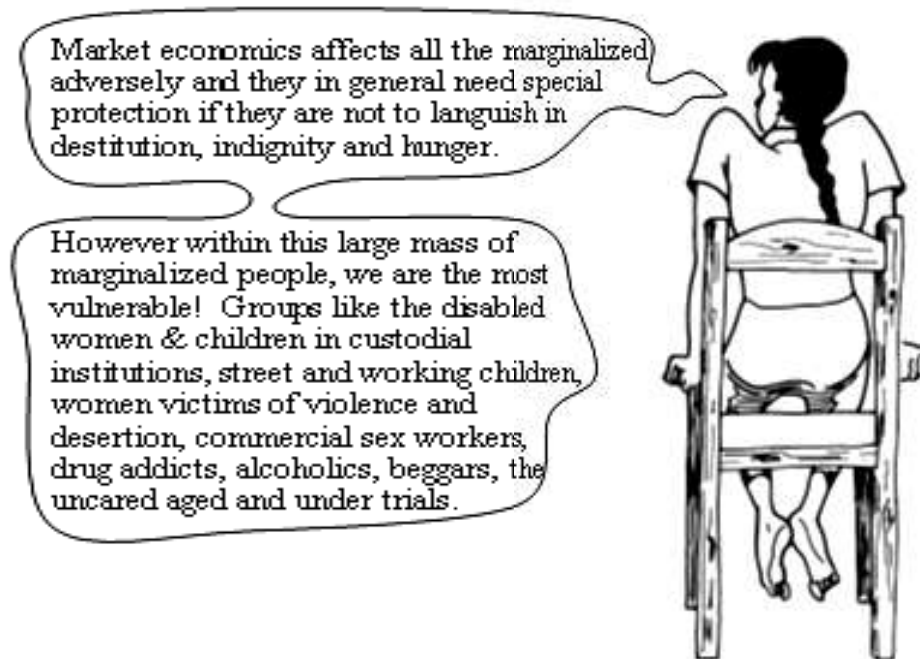
3. Measures for Self-esteem, support Services and Morale:

- a. Enable socially useful activities for the aged, for their own self-esteem e.g., tuitions, adult literacy classes, visiting patients in hospitals, Red Cross activities, humanizing children's and women's institutions as visitors or foster-grandparents etc.
- b. For economically and emotionally dependent aged, organise sponsorship programme by citizens' / NGOs, under which monthly payment is made and emotional bonds developed with identified aged persons
- c. Involve community, religious and social organizations etc. in all these interventions

4. Old Age Homes and Alternatives:

- a. For old people without care of children, enable group living schemes, by convergence of various government and private housing schemes e.g., by earmarking and allotment of suitable land for housing schemes, formation of housing co-operatives, channelizing of soft housing loans, allotment of houses of Indira Aawas Yojana and other housing schemes wherever eligible etc.
- b. For physically dependent and economically dependent aged persons without family support, create institutions, ensure clean cheerful surroundings, simple nutritious food with variation, a daily routine including recreation and minimal productive activity (e.g., horticulture, chalk-making), structured regular friendly visitors, and trained and motivated managers.

How Structural Adjustment affects the Most Vulnerable !



We on the one hand, critically depend on state support to lead lives of even minimal dignity and self-reliance and, on the other, lack organization & pressure groups.

We are often called the last in society. But we want to emphasize that many of us play an important and vital economic role.



Other groups within this last of society who are unable to contribute economically should be seen as society's victims, to whom society owes compensation. Compensation they cannot claim due to their powerlessness.

The willingness of a society to accept its responsibility towards these sections is a measure of the ethics and morality of a civilization!

General Principles of Interventions to Assist the Vulnerable

Interventions for the vulnerable sections should be based on the following principles:

- ◆ The central responsibility of the State for social welfare and security of all, especially its most vulnerable citizens should not be minimized. We must work for policies & initiatives that make this possible.
- ◆ The distinct nature of the problems, vulnerabilities, handicaps, needs and also the potential of the specific group should be understood. We must build this understanding with the full involvement of the group - not for them but with them
- ◆ Locate 'do-able' local solutions with local resources and local leadership and with professional technical help whenever required.
- ◆ We must emphasize sustainability and replicability and involving the community and the target group actively in the initiatives
- ◆ All interventions should ultimately lead to dignity and self reliance of the beneficiaries, not charity and dependence.

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