

IN THE GUISE OF HUMAN DIGNITY

*A report on the mass hysterectomies performed in
February 1994 on mentally handicapped women of
the Government Certified School of Mentally
Deficient Girls, Shirur, Maharashtra.*

INTRODUCTION

On February 24th 1994, a Public Meeting was organised to draw attention to the barbaric act of mass hysterectomies being performed on mentally handicapped women of the Government Certified School of Mentally Deficient Girls, Shirur, near Pune, Maharashtra.

Representatives of Stree Kruti, Shramajeevika, Forum Against Oppression of Women, Lokashahi Hakk Sanghatana and National Addiction Research Centre spoke. In addition two parents of mentally handicapped persons addressed the meeting. The discussion that followed showed that people were very agitated about the issue, and, there was a general demand that something further should be done towards publicising the issue and raising the awareness of the general public on matters like, the status of mentally handicapped persons, the role and attitude of the State in the care of mentally handicapped, the issue of technological solutions to social problems, the responsibility of the State to look after the health of its citizens both able bodied and handicapped.

A resolution was drafted accepted and circulated to the Press. Through common consensus a decision was taken to publish a report that would address the issue from the perspective of the rights of handicapped persons and the responsibility of society to ensure that they lead a life to the fullest extent of their capabilities.

Resolution passed at meeting held on February 24, 1994 to condemn the Maharashtra Government's decision to hysterectomise mentally handicapped women:

This meeting condemns the heinous abdication of responsibility by the State towards the mentally handicapped. The hysterectomies on the women in the Shirur home are only a published instance of this. Such neglect is part of the general abdication by the State towards the livelihood and well-being of the able bodied as well as the handicapped people in our country.

Under pressure from the World Bank-IMF combine, the State is further giving up even the very measly provisions it has been making for social welfare so far.

We commit ourselves to raising the public consciousness regarding this problem, the capability as well as the right of the handicapped for

decent life of dignity and social integration and work, and the national context in which this right is being bypassed. We shall do whatever we can to bring all such atrocities to public light.

An Outline of Events

On February 4 1994, The Indian Express carried a front page report entitled 'Wombs of 25 women to be removed'. It began, 'A leading city gynaecologist has an unusual project lined up for this weekend'. He would "surgically remove" the wombs of 20 to 25 women each of whom has severe retardation. The mass surgery was to be performed at Sassoon Hospital, Pune. The Rotary Club of Pune was to foot the bill. Dr. Sheth (the Gynaecologist) maintained that the women are obviously unable to care for their personal hygiene. The report quotes Sheth's claim that these women often became the victims of sexual assault that results in pregnancy and that he had already performed around 100 such surgeries. He informed the news service that Vandana Khullar, Director, Department of Women, Child and Handicapped Welfare, had requested him to perform the surgery. He quoted from Khullar's correspondence to say that she felt it would be highly appreciated if he would perform the hysterectomies.

Clearly Sheth, Khullar and the Rotary Club, Pune believed that they could pose as do-gooders and hoped to obtain some promotional publicity out of their hysterectomy plan.

Women's groups and social activists protested. Activists of Medico Friend Circle, Janawadi Mahila Sanghatana and Stree Kruti held a dharana outside Sassoon Hospital. The class four employees of the hospital also participated in the dharana. Ahilya Rangnekar who felt the publicity given to the camp was an intrusion into the privacy of these women, contacted Sharad Pawar who was in Delhi. Pawar ordered the operations to stop. This brought the incident additional publicity. Meanwhile the team of doctors and Khullar had tried to 'reason' with the protesters.

On February 4 the protest not with standing, operations were performed on 11 girls between the ages of 13 and 35. The Chief Minister later gave the green signal for hysterectomies to be performed on women who were mentally handicapped but said they need not be done on a 'mass' scale. To quote the Indian Express of February 14, 1994, 'the Chief Minister said he had entrusted the

responsibility jointly to the authorities and the doctors. He assured that there would be no intervention on behalf of the Government in the decision taken by them'.

Khullar had earlier recommended 30 girls for the surgery but after tests 18 were 'found suitable' (Daily 7-2-94). She claims that "this proposal was rooted three years ago but none of my predecessors took a bold decision because it was a controversial issue fraught with risks. I felt that the girls would be able to live with dignity after the operations so I decided to go ahead with it." (emphasis ours) Frontline March 11, 1994.

The previous Director, Avinash Dharmadhikari, had initiated a debate on the issue but had refrained from taking any action. Khullar, admitting loftily that the issue was 'fraught with risks', unilaterally decided to take 'the bold decision' because she 'felt' she should go ahead.

Let us proceed to observe how (for the sake of the argument put forward by Khullar, Sheth and many others) these women after their surgery could conceivably live a 'life of dignity' at the Shirur home.

The conditions of the Government Certified School for Mentally Deficient Girls, Shirur

Located 65 Kilometers from Pune, the Shirur Home has 49 inmates, all remanded to custodial care by the Juvenile Court. The institution falls under the jurisdiction of Department of Woman, Child and Handicapped since June 1993. It is the only Government run school for persons with a mental handicap in Maharashtra. The government allots Rs. 4.65 lacs annually for its expenses.

A majority of the girls suffer from serious ailments. Ten are epileptic, five are deaf and dumb and two cannot walk. Some have tuberculosis and others have scabies. All are mentally handicapped, anaemic and malnourished. 'Three quarters of them have an Intelligent Quotient of 20, the rest are slightly better with the maximum Intelligent Quotient being 60. Though the Government has sanctioned 18 posts, four, that of their teachers are vacant for a couple of years.' (Frontline March 15, 1994)

In November 93, three girls died due to anaemic conditions. More recently in March 1994, even after the spotlight on Shirur, another girl died due to anaemia and dysentery. The Authorities clarified that the girl was not hysterectomised. Varsha Kulkarni, a journalist with 'Sakal' wrote in February 1991, that the conditions were appalling and that six girls had died in the preceding six months.

The Home is situated in a drought prone area and suffers from scarcity of water. The Metropolis of February 12, 1994 states that there are 10 halls in the Home which 'reek of urine and excreta'. Superintendent S. M. Sonawane who has been there for two years claims "All of us are completely desensitized to it -- with two caretakers working at any given time, how can we take care of the property?"

Though fairly well ventilated the identical 30 by 25 feet rooms are bare and cheerless. There is no educational or training equipment. The only diversion is a lone television. There is one craft teacher who has no training in dealing with mentally handicapped children. 'There seems little informed effort to train the girls for activities for daily living. Much of the responsibility for actual physical care of the girls seemed to be performed by some of the more able inmates. The inmates who could not perform these tasks just sat around most of the time'. (Report on Shirur, members of 'Action for Rights of the Child'). There are two other institutions on the campus of the Shirur Home. There is no interaction between these three institutions either.

It is a well established fact that when mentally handicapped persons are not provided with stimulating activities they tend to use the excretions of their bodies (urine, menstrual matter, excreta etc.) as substitute for the missing stimulation. The persons responsible for their care ought to know this and provide suitable training. Most significantly three posts for teaching staff which include two teachers specially trained to deal with mentally handicapped persons have not been filled since 1990-1991. (Times Of India). The Home has no vehicles for taking the girls anywhere, for an outing or even to a hospital, and hopes to acquire a community washing machine, solar water heaters and an ambulance.

The conditions at Shirur are horrific -- not only that there is absence of elementary cleanliness but even more so because nothing and this means nothing is done to train these women to help their personal physical routine or their all-round development. By contrast the authorities have shown great enthusiasm to perform these mass surgeries. They have taken the initiative to organise the

funds, the medical facilities, and the surgeon's services. Indeed they have conducted tests to select the women who would be operated upon. There is no dearth of persons in our community who are trained in the care of mentally handicapped persons. In fact, as we shall show later, given the will, the patience and the effort any humane person can work wonders with persons with handicaps.

Where the general health of the girls is concerned too there is evidence of callous neglect. Most rampant are complaints of anaemia and skin diseases. A good diet and clean surroundings coupled with training can overcome both conditions. The girls suffering from anaemia, has been presented as another reason for advocating hysterectomy. Our 'experts' prefer hysterectomy to iron supplements!

It is glaringly obvious that the hysterectomy option has been chosen because, for the caretakers it means that much less work and for the authorities less expenditure incurred in terms of saving on salaries of the attendants. It then seems to have done away with one stroke both, the problem of 'menstrual hygiene' and that of 'unwanted pregnancy'.

It has been said in various places that these women are focus of sexual abuse. As the various organisations that protested against the hysterectomies have pointed out, the elimination of the possibility of pregnancy after sexual assault in fact increases manifold the possibility of sexual abuse. Moreover, sexual abuse in a Government institution is nothing short of custodial rape.

The crux of the issue is that the government is guilty of gross abuse of authority and abdication of responsibility. To exercise its rights as guardian of the handicapped persons in its care, the government must first discharge its responsibilities.

A Glimpse of some other Institutions that care for Mentally Handicapped Persons

Are conditions at the Shirur Home inevitable? Do all institutions have to have vacancies unfilled for three years? Do they all reek of urine and excreta? Do they advocate the removal of the uterus of their mentally handicapped women? We make no claims of presenting any 'models' but wish to merely show that even

within the existing boundaries of expenses and human resources, conditions can be somewhat more hygienic and humane.

Institute Of Human Behaviour and Allied Sciences at Shahdara, Delhi

This is a government run centre at Delhi housing to inmates, many mentally handicapped, who have been abandoned by their families. At any given time there are four attendants looking after them. The authorities have never had uteri of the women removed. Though the attendants claim that it is a problem when the women menstruate they take care of them. Some women have been there for thirty years.

The Director of the Institute, Dr. S. D. Sarma has gone on record a number of times since this incident to denounce the practice of forced hysterectomy on mentally handicapped women. "The test of any civilized society lies in the way it looks after those that cannot look after themselves". He also claims that this would lead to further sexual exploitation of women with mental handicaps.

Beru Matimand Pratisthan at Kothrud, Pune

This is a privately funded and run institution where 30 women are looked after. They accept persons with severe handicaps. For post-puberty women they have made hysterectomy a pre-condition for entry. The institution which is clean and hygienic is funded and run by Shankar Beru.

Mankhurd Children's Home, Bombay

When members of this team visited to make inquiries regarding the stand that the authorities take on admitting women they were told unofficially that they expect the guardian of the women to perform hysterectomy on their wards before admitting them.

Asha Daan, Bombay

Asha Daan is a home for dying destitutes and handicapped persons at Sankli Street, Bombay run by nuns belonging to Mother Teresa's religious order. A

member of our team visited Asha Daan and was shown around. The home consists of two large rectangular sheds, well ventilated, clean and welcoming, with several plants outside and pictures and displays on the walls. Fifty girls are cared for. There is no odour of urine or excreta.

Many of the girls who are not severely handicapped go six days a week to the 'Anza Special School' which is a short distance away. Here they are taught various skills that help to make them more independent and dextrous with their hands. The nuns maintained that they have never performed hysterectomy on any of their girls and would never think of even doing so. They train the girls. Over twenty of the women can manage by themselves, twelve cannot and have to be helped. The nuns admitted it was a difficult task but that they coped. The more capable girls also helped the less capable ones. They also performed many of the cleaning and washing chores as a matter of routine.

We have given very few instances above. Parents and teachers of mentally handicapped persons stress that training, patience, love and sustained effort can work wonders with mentally handicapped. The mentally handicapped who can be trained up to a very small degree need to be helped and cared for to a larger extent. It is how the administrators of each of these institutions views the problems and rights of mentally handicapped persons that matters. Whereas for the Institute of Medical and Allied Sciences and Asha Daan hysterectomy is unthinkable, for Beru Matimand Pratisthan and for the Government Certified School for Mentally Deficient Girls, Shirur, it is imperative that it be performed.

Hysterectomy -- Its types and possible side effects

Hysterectomy is the surgical removal of the uterus. The procedure can be carried out in three ways:

- i) *through an incision in the abdomen.*
- ii) *through the vaginal passage where instruments are introduced and the uterus detached and removed. This is a blind procedure and requires a great deal of expertise and skill.*
- iii) *the above procedure is carried out with the help of a laparoscope to view the insides of the abdomen.*

The surgery performed by Dr. Shirish Sheth on the mentally handicapped women is termed 'trans-cervical resection of the endometrium. This is a sophisticated, expensive and high tech procedure.

If the ovaries are also removed with the uterus, hormonal imbalances occur in the body specially if the removal is before menopause. Women have been known to suffer from depression, loss of a feeling of womanhood and even increased risk of heart attacks after hysterectomy. There is not adequate research on the side effects of hysterectomy.

Hysterectomy is medically advised when uterine tumours are present, when there is severe degree of uterine prolapse, uterine rupture or gangrene due to any cause, chronically bleeding uterus which cannot be managed by other means, infective conditions in the uterus like pyometria. Hysterectomy to remove a healthy uterus to stop menstrual bleeding in pre-menopausal women with a mental handicap is not known to be standard procedure anywhere in the world. In various countries there is an on going debate on sterilization of persons with handicaps but we could find no instance of hysterectomy for the sake of hygiene.

Shirish Sheth who was the former head of the Federation of Obstetrics and Gynecology Society of India proclaims, "Removal of uterus is the only solution science has, as far as severely mentally retarded women are concerned. It is a well known fact that such women are totally incapable of managing their periods and make a mess of it. Even assuming that we can arrange for people to clean up the mess, these women are still exposed to the risk of recurring infection due to lack of personal hygiene."

Among 'normal' women hysterectomy is advised as the lesser evil when conformed with tumors, infections etc. In this incident a major surgical procedure is performed on women who cannot give informed consent, who cannot choose because they are limited by their mental and physical conditions. They thus become helpless victims of an institution that is meant to look after their interests, their persons, their all-round development and care.

Professor Sunil Pandya who runs the neuro-surgery Department at KEM Hospital, Bombay cautions, "Medically speaking hysterectomy carries all the risks that are inherent in any surgical intervention. The risk in this surgery is that the ureters carrying urine to the bladder run very close to the uterus. In Dr. Sheth's hands the risk could be close to zero. But once the flood gates are opened

the State could call upon even the least experienced surgeon to perform the surgery and then the risks go up."

Not any attention is focused on what special side effects may occur on the physical or mental balance of a person already having a handicap. What about the trauma of surgery, the effects of general anesthesia, the post-operative phase. The inter-relationship between various organs is not totally known to medical science. it is common knowledge today that tonsils and appendicitis which were earlier performed with great ease are now advised with equal caution. To call the uterus a useless organ for a woman with mental retardation because she may never bear a child and can therefore dispense with it, is typical of the reductionist attitude and approach of many doctors where each organ is meant to have a fixed independent role in the body.

Barely hidden below all the protestations about hygiene runs the thread of the taboos associated with menstruation. Khullar, Sheth and Sonawane refer to menstrual blood as 'mess'. That menstruation is something that is dirty, polluting and harmful specially to others is part of our social understanding. Rather than educating the attendants regarding the simple and biological causes of menstruation, the authorities found it more convenient to remove the uterus itself. The government has exploited this taboo and mutilated the bodies of women under its care. The authorities need to expend less energy and expense in terms of hygiene as well as safeguard from sexual abuse.

The logical conclusions flowing from accepting hysterectomy on women with a mental handicap

A very direct result of allowing such surgeries to become accepted and routine is the grave danger of removing other healthy organs which fetch a price in the national and international markets. Once a person is under general anaesthesia, there is no dearth of unscrupulous surgeons who can remove any other organ. Removal of ovaries for use in in-vitro fertilisation experiments is now a growing phenomenon.

On the strength of the argument of 'menstrual hygiene' and 'useless organ' we can as well advocate lobotomy for mentally ill patients. Removal of the lobe does not interfere with the basic function of survival and will help the staff working

in our mental institutions because they will have fewer problems in dealing with the inmates.

There is danger that people belonging to sections such as mentally and physically handicapped, the very destitute and old, will be used as guinea pigs to try out new surgical procedures and drugs, all in the name of protecting the handicapped persons themselves from this or that inconvenience or danger.

Stretching the stand of Khullar on 'hygiene' and 'opportunity to live with dignity', one may in future hear of colostomies with plastic bags worn on a belt for women and men with mental handicaps who cannot control their bowel functions. Will the same methods of hacking and eliminating be applied to urine control, slackness of the jaw, drooling, uncontrollable shaking of the limbs and head?

We present such horrendous possibilities not only for the sake of argument but for the grave need to be watchful of such atrocities. In societies where one group of people is not deemed to have equal rights as others worse atrocities have been performed by those in power.

Indeed Dr. Suresh Deshpande of IMA Pune goes on record to say, "The issue of sterilisation of these children is subsidiary. If society is in such a stage that these or for that matter any children cannot be protected from sexual abuse sterilisation or hysterectomy will be too inadequate a procedure. These severely retarded girls need permanent closure of their vaginas. We are too timid to talk of this."

Interestingly none of these messiahs of modern science refer to the need for more attendants, trained caretakers, increased budgetary allocations, accountability of staff and officers who run our institutions, more recreational facilities, employment avenues, medical care, psychiatric counselling or simply protecting the rights of handicapped persons.

The responsibility of the State towards the care of handicapped persons

All through this controversy, the administrators and doctors are putting forward a very misleading argument. It is pointed out that individual families opt for performing hysterectomy on their mentally handicapped wards. Therefore this

is an accepted practice, and activists are protesting simply because the government decides to take the same action. Certainly some forceless feel compelled to perform this surgery due to constraints of money, time and persons to attend to their children. Even so they take the decision after much thought and many attempts at training. For the government to be waving this banner is only begging the question.

It is primarily the responsibility of the State to look after persons with handicaps and assist families and communities. Because there is no help forthcoming, no infrastructure created, families are compelled to cope on their own within enormous constraints. They do know of the horrific conditions prevailing in homes.

For the authorities to take this stand is brazen. Not only do they turn a blind eye to millions of handicapped citizens who ought to receive assistance and care, but even to those tiny minority that are in institutions they have not the will to guarantee a decent existence.

To quote Kalpana Swaminathan a pediatric surgeon, "Don't burden the parents with this responsibility too. It is cruel to mock them saying "we did it because you asked for it". We pay the State to support and protect these children and their parents not to undermine and misguide them."

In such a society as ours having a mentally handicapped child is seen as a stigma in itself. Families have to overcome their own sense of inadequacy and learn to cope with their situation. Those in positions of authorities and power ought to focus their attention on the psychological and physical repercussions of sexual abuse rather than harp on 'unwanted pregnancy'.

Budgetary Allocations : Spending on health and social services and further trends

It is hardly surprising that the government treats its handicapped in a callous and cruel way. The same treatment is meted out to its able-bodied citizens who are undernourished, unemployed and homeless. Closures, retrenchment and unemployment are the order of the day. In the name of the technological progress already high unemployment and grenading poverty are on the rise.

Seven to eight million people are added to the arms of unemployment each year. There are more people on our employment exchanges than on those employed in the organised sector, 3.6 crores as opposed to 2.5 crores. Here the term 'organised sector' denotes those units employing more than 25 people per unit (not organised in terms of unionised or getting benefits such as provident fund, gratuity, pension, dearness allowance etc.). The conditions of living for the vast majority of our able bodied people is wretched.

In keeping with these overall policies of the government which are becoming harsher due to structural adjustments insisted upon by the World Bank, spending on health and welfare is very low. Nullifying even this measly allocation is rampant corruption, mismanagement and negligence. Welfare expenditure which is but an apology for the fear is going down both in fiscal as well as real terms. The World Bank Report 1993, Health, has asked for 'further cuts in welfare expenditure and increasing participation of the private sector in health'.

This report's purpose is to initiate a dialogue on structural adjustment which will influence the policy on health. 'Participation of the private sector' is a real and sanitised way of saying that only those who can afford to pay for medical attention will receive it. In other words, a citizen has no right to medical care.

We can visualise how grim the situation is if we note that the Shirur Home is the only government run home in Maharashtra. All other institutions are aided by way of grants. These are run by non-government organisations over which the government has little control or supervision. By way of grants the government pays 100% of staff salaries, building rent and 66% of all other expenditure. In addition it pays Rs.250 per month per beneficiary.

The Maharashtra State Budget for 1993-1994, provides Rs.35 crores for social welfare of which 17.59 crores is allotted for welfare of handicapped persons. The break up of schools for handicapped persons obtaining government grants is as shown in Table 1 below.

If we take the population of mentally handicapped persons in Maharashtra as 2% of the population of the State, (this is the general rule for all societies but in an impoverished society such as ours it is bound to be a little higher) then the number of mentally handicapped persons is 1.6 million. Further if we take the number of people between 5-20 years age as 37% of any population then the

number becomes 59.2 lacs. One can imagine how 59.2 lacs children can be accommodated in 65 schools. The government cannot even begin to address the problems of education and care of persons in a woefully inadequate programme. Even this is sought to be further trimmed.

Table 1 : Number of schools for the handicapped persons

Description of the Institution	Number of Schools
1) For mentally handicapped	65 (9 Workshops, 9 Residential schools, 45 Day schools)
2) For deaf and dumb	105
3) Blind	41
4) Physically handicapped	41

Table 2 : Maharashtra Plan for Education and Rehabilitation of the Disabled

Description	Year Expenditure in Lacs.	
	92-93	93-94
1) Government Institutions	148.23	175.97
2) Help to N.G.O.s	1116.31	875.70
3) Artificial limbs etc.	5.60	5.80
4) Help for business	2.50	2.50
5) State government Scholarships	105.27	201.10
6) Self-employment Capital	29.04	25.49
7) Government Prize Scheme	2.12	0.90
8) Guidance Counselling Centre	16.23	21.88
9) Co-Operative Societies	2.00	2.20
10) Prizes for High school and Junior college students	2.01	2.21
11) Training of Teachers	1.70	1.65
TOTAL	1431.01	1315.40

Taking the country as a whole the planned expenditure on social services was 0.8% of G.D.P. in 1989-1990. This fell to 0.6% G.D.P. in 1992-1993. Further the term Social Services includes such diverse fields as Information and Broadcasting, Health and Family, Labour and Labour Welfare, Welfare of Scheduled Castes and Tribes.

As can be seen in Tables 2 and 3, the allocated amounts have fallen in both nominal and real terms in recent years.

Table 3 : Budget of the Union Ministry Of Welfare for the Handicapped

Description	Years			
	Expenditure in crores			
	91-92	92-93	93-94	94-95
1) National Institutes for Blind Deaf, Mentally retarded & Orthopaedically handicapped	15.54	14.62	15.12	15.53
2) Assistance to Voluntary Organisations for welfare of handicapped	4.7	7.7	8.15	8.7
3) Technology Development project	0.85	0.4	-	-
4) Spinal cord injury centre	0	0.1	-	-
5) Grants-in-aid to spastics society	2.5	-	-	-
6) Other programmes for welfare of handicapped	17.74	25.89	6.87	5.71
7) Aids and Appliances for handicapped	-	-	10.00	10.00
8) Referral rehabilitation of handicapped	-	-	12.75	12.75
<i>Total - - - -</i>	<i>41.33</i>	<i>48.71</i>	<i>52.89</i>	<i>52.69</i>

Let us take conservative estimate of inflation at 10% per Year.

In 91-92 to 92-93 marginal rise in real terms.

92-93 to 93-94 fall in real value.

93-94 to 94-95 fall in nominal as well as in real terms.

The vast majority of mentally handicapped persons are cared for within their families. In fact, families allocate funds from their meagre family budgets. As the real value of those family budgets falls many poor families will be compelled to abandon their wards with mental handicaps. With the existing paltry State support also shrinking, many more persons with mental handicaps will have to face the harsh realities of existence totally unsupported and unprotected.

Without Comment

Vandana Khullar, Director, Women, Child and Handicapped Welfare, Maharashtra: "This is an accepted medical procedure in the case of a mentally retarded woman, not merely to safeguard her against possible sexual abuse but also to enable her to live in normal hygienic conditions."

(Indian Express February 14, 1994.)

"What is fascist about ensuring that a woman is not saddled with a child she does not want or know how to handle."

(Indian Express February 14, 1994.)

Dr. Shirish Sheth, Gynecologist: "Removal of the uteri is the only solution science has as far as severely mentally retarded women are concerned. It is a well known fact that such women are totally incapable of managing their periods and make a mess of it."

(Independent February 17, 1994)

Dr. Arvind Sangamnerkar, President Pune Obstetric and Gynaecological Society: "Knowing the kind of care that is given to any person in a public hospital how can we expect better care for these women?"

S. M. Sonawane, Superintendent Government Certified School for Mentally Deficient Girls, Shirur: "People are making a fuss about these operations but you should come and stay with these girls. They all mess up with their menstrual discharge. Being anaemic they feel fatigued during their periods. Many cannot withstand menstrual pain."

(Frontline March 11, 1994)

Praful Bidwai, Journalist: "The fact of its irreversibility makes it imperative that hysterectomy should be a procedure of last resort, to be used only in the rarest of problem cases and exceptional circumstances. In Maharashtra it has been

promoted as the first, most favoured method of dealing not with a medical or social problem but as a means of allowing the State to evade its duty to look after disabled women."

(Frontline March 15, 1994)

Dr. Anant Phadke, Activist Medico Friend Circle and Lok Vigyan Sanghatana: "Instead of trying to tackle social problems, a convenient technical process of removing the uterus has been devised. This surgical solution does not benefit the hysterectomised woman because normal menstruation is not a disease to be eliminated."

(Independent February 17, 1994)

Dr. Kalpana Swaminathan, Pediatric Surgeon: "Those of us who work with babies particularly deformed and disabled find ourselves constantly questioning our conclusions. This skepticism is part of the job. Without this humility there would be no understanding no progress."

The Rights of Handicapped Persons

All human rights and fundamental freedoms are universal. Persons with disabilities have the same rights to life, to education, to employment and active participation in all aspects of society. Society and the State have an added responsibility towards the care of handicapped persons because they cannot by virtue of their handicap, deal with certain aspects of their day to day life. Therefore it is the right of a handicapped person that he or she receive that extra assistance to make life as full and rich as possible – not as charity but as of right.

Merely feeding, clothing and housing handicapped persons is not enough. Attention has to be paid to their training, recreation and employment. Every handicapped person has a right to the kind of employment she or he is capable of doing to feel an equal and contributing member of society.

A general thumb rule is that 2% of any population is mentally handicapped. This is a huge number of people who today are almost totally outside the pale of employment or participation in public life.

The State should take the initiative in providing infrastructure and offer professional guidance and help to the already existing family and community based care that exists. Help should be provided at various levels to handicapped

persons and their families in terms of financial assistance, employment opportunity, medical aid, counselling, schools and recreational facilities.

It is a well known that many mentally handicapped people are very thorough and careful with their tasks once they have mastered them. Many can be employed in packaging and assembling industries, in shops as caretakers.

Mentally handicapped persons are an invisible section of society partly due to there being no infrastructure to absorb them into day to day life and partly due to the embarrassment and stigma that families feel. Many look at them with pity or horror. We have to examine our attitudes and help and encourage handicapped persons to take their rightful place in social life. This debate on hysterectomies performed on mentally handicapped persons has served to focus attention to a small degree on this problem. Many members who participated in this report discovered so many aspects concerning handicapped persons that they may otherwise not have thought of.

By shutting out our mentally handicapped citizens society is losing on their productive capacity and we, the so called normal able bodied, the opportunity to integrate and mingle with those who are in every sense our fellow beings.

CONCLUSIONS AND DEMANDS

Of the 18 women 'selected' for hysterectomy at the Shirur Home, 11 have undergone surgery. 7 women (at least technically) can be hysterectomised at any time. The Times of India of April 6, 1994, carries a small news report of a query in the Vidhan Sabha and the Chief Minister's reply. Mrs. S. Phadanvis (B.J.P.) wanted to know "What arrangements would be made all over the State to carry out hysterectomy on all mentally retarded girls." We quote further from the report. 'Pawar said he had met a number of experts, psychiatrists and social-workers -- Most of them suggested that publicity should be avoided in this connection. The Government had accepted their suggestion.'

It is crystal clear that the threat of forced hysterectomy hangs not only over the seven girls at Shirur but over all mentally handicapped girls in the State. An elected member of the Assembly would like to know of the arrangements 'made all over the State.' Further in future these operations will be performed in secrecy. The Chief Minister has given the green signal and has openly cautioned

the concerned officials to keep the matter from the public eye. This is a typical combination of treachery and dishonesty.

Many have taken the position that hysterectomy of mentally handicapped women be performed as an option of last resort after all efforts at training have failed. We strongly disagree and demand that these needless mutilations of women's bodies be stopped. Instead the State must make more financial provision to employ a larger number of caretakers. The 'last option' approach is bound to be misused by the State, which as we have demonstrated cares little for the rights and welfare of disabled persons.

We do not criticise those individual families who take this step for the very substantial reasons noted earlier in this report. We strongly condemn the practice of those public institutions who insist on performing the surgery, or ensure that it is performed by family members before admitting their wards.

We demand that the Maharashtra Government

- 1) *Withdraw the practice of forcible hysterectomy of mentally handicapped girls.*
- 2) *Fill the vacancies for trained teachers at Shirur without further delay.*
- 3) *Create training, recreational and vocational guidance facilities at the Shirur Home.*
- 4) *Improve the general sanitary conditions and health of the women at Shirur.*
- 5) *Provide opportunities for outings and interaction of the women of the Home with other sections and with outside world.*
- 6) *Employ more attendants to have better round the clock care of the women.*

We strongly feel that this heinous act be publicised and that we should struggle to put an end to it. The repercussions of accepting such fascist onslaught will not be confined to removal of a healthy uterus alone or to mentally handicapped persons only.

This report is partisan with handicapped persons everywhere. It is an attempt to place in proper perspective the question of the Rights of Handicapped vis-a-vis the State, and its responsibility, not only towards them, but also towards vast majority of the exploited and oppressed people of our country.

This report is brought out by a team of representatives of Stree Kruti, Shramajeevika, Forum for Women's Health, Forum Against Oppression of Women, Lokashahi hakk Sanghatana, Ms. Rubina Lal, teacher of the S. P. J. Sadhana School for Mentally Handicapped and Ms. Mariam Kanga a Social Worker. The last two members are both parents of mentally handicapped persons.

Suggested contribution: Rs. 2

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