In the face of AIDS - this new, unheralded global crisis - we should all be humble. But we should be resolute. We should think of the many who this day will become infected and those who will learn of their infection. We should think of their families, parents, lovers, friends. We should spare thoughts for the healthworkers who will toil courageously over them - often with no drugs, always with no cure. Learning from past errors of cruel and inefficient laws we should resolve, this time, to do better. Stigma should have no dominion.

Hysterectomy in the mentally handicapped.

An abridged version of the statement issued by PARYAY.

(PARYAY is a group fostering hrrmane alternatives to hysterectomy in the mentally handicapped. Members can be contacted c/o Aalochana, 'Kedar', Kanchan Galli, Off Law College Road, Pune, 411 004, INDIA.)

We oppose the decision on hysterectomy in severely mentally retarded women in the asylum run by the government. The action was unjustified and unethical for the following reasons:

A. The operation was not medically indicated

1. Menstruation, even in the mentally handicapped, is not a disease to be eliminated. Hysterectomy has been carried out for the convenience of the caretaker institutions and not for the health of the mentally handicapped women. Would a 'normal' woman undergo this operation just to get rid of the 'trouble of menstruation', even after the completion of childbearing?

Since excreta from bowel and bladder need attention in the severely mentally handicapped, similar care can be provided for the outpourings of the uterus. How can hysterectomy be justified on the argument that it is the removal of a 'useless organ'? The utilitarian principle involved in advocating this operation has the sinister implication of justifying mercy killing of 'useless' people.

2. Hysterectomy is major surgery with a mortality rate of l-2 per 1000 operations and an even higher complication rate. **There is a widespread misconception, even among doctors that removal of the uterus, without removal of the ovaries has little or no long-term health consequences for the woman. This is not true.** 'Operative Gynaecology' by Telinde and a number of gynaecology books, state that 3-5 % of all women undergoing hysterectomy may need a second operation - the removal of their ovaries. Part of the blood supply to the ovaries is through the uterine artery. As this supply can be compromised by hysterectomy, ovarian function may be impaired. This results in the Residual Ovary Syndrome - a painful adnexal mass in the pelvis, general pelvic discomfort and pain during sexual intercourse. (We must not forget that one of the reasons for hysterectomy is to prevent pregnancies after forced intercourse).

3 Even if the ovaries are left in, their function often recedes after hysterectomy, lowering the levels of estrogen in the body. This may lead to cardiovascular disease and osteoporosis. Subjecting young girls to the operation therefore has severe and long term consequences. The fact that these operations are performed on healthy women compounds the risk.

4 Such hysterectomy is not recommended by any standard textbook of gynaecology or psychiatry. An extensive search through Medline and Popline shows that it is not an accepted practice in developed countries. Most of the literature discusses tubectomy and even this operation is approached

cautiously, with paramount stress on the welfare of the woman and not the convenience of the caretaker institution.

5 No academic body in India has discussed the ethical aspects of such hysterectomy or recommended it. Some experts (such as Dr. S.D.Sharma, Director of the Institute for Human Behaviour and Allied Sciences in Delhi) have opposed the practice. Many Indian institutions for the mentally handicapped (Sadhana School and Asha Daan in Bombay, and the low-budget rural school Jeevan Vardheeni in Saswad) do not favour it. If adequate care and training are provided to the mentally handicapped, hysterectomy is unnecessary.

B. The State has failed in it's duty

1. India can afford minimum facilities for the care of its handicapped people. This is 'not possible' today because the government spends too little on health and social welfare. In the 'Health For All' Declaration of Alma Ata (1978), India agreed that 5% of the Gross National Product be spent by the State on health care. The Indian government spends 1.17 % of it's GNP on health! India's health budget has **decreased** over the years. To conduct hysterectomy on the mentally handicap&d on the excuse that there are no funds is adding insult to injury.

2. The human rights of persons in State custody need to be strengthened, not weakened. Removal of an healthy organ without even providing basic care and facilities erodes their human rights.

3. Women in some State-run institutions for the mentally handicapped are not given underclothing as 'they may strangle themselves with the garments'. Whilst men are provided shorts, **the only clothing that women wear at all times (even when menstruating) is a smock that goes over their heads.** The other reason stated was that rural women are not used to undergarments. Is it surprising that women handle their menstrual flow?

C. Parents' dilemma

We are aware that the issue of hysterectomy for the family looking after a mentally handicapped daughter is more complex than that in when she is a ward of the State. There is no State support to parents of the handicapped in India. The mother of the handicapped child functions under severe physical and emotional stress as even routine housework is not shared between men and women. The mother performs numerous tasks and looks after the mentally handicapped child. She faces the double stigma of not only having produced a daughter but one that is retarded. The general attitudes towards girls, menstruation, non-marital pregnancy and the mentally handicapped aggravate the dilemma of the parents. The decision to permit hysterectomy in their daughter is made to provide a partial solution to the parents' seemingly endless problems.

D. 'Paryay' suggests the following alternatives

1. Increasing personnel, financial and infrastructural support to the State-run institutions for the mentally handicapped.

2. Qualitatively and quantitatively improving the number of homes for the mentally handicapped.

3. Provision of physical, intellectual and psychological stimulation to mentally handicapped children without preconceived biases.

4. Training mentally handicapped children in personal hygiene (including menstrual care) through repeated and innovative inputs. Providing adequate undergarments and menstrual padding to all girls in State homes.

6. Changing the form and content of training for teachers and caretakers so that biases against women's bodies and menstruation are countered.

7. Providing security to children from sexual and physical abuse in all the homes for the mentally handicapped.

8. Increasing the health care budget for the handicapped in absolute terms and as percentage of the Gross National Product.

9. Providing financial support, creches, day care centres, counseling services, rest and recreational support to parents of the mentally handicapped.