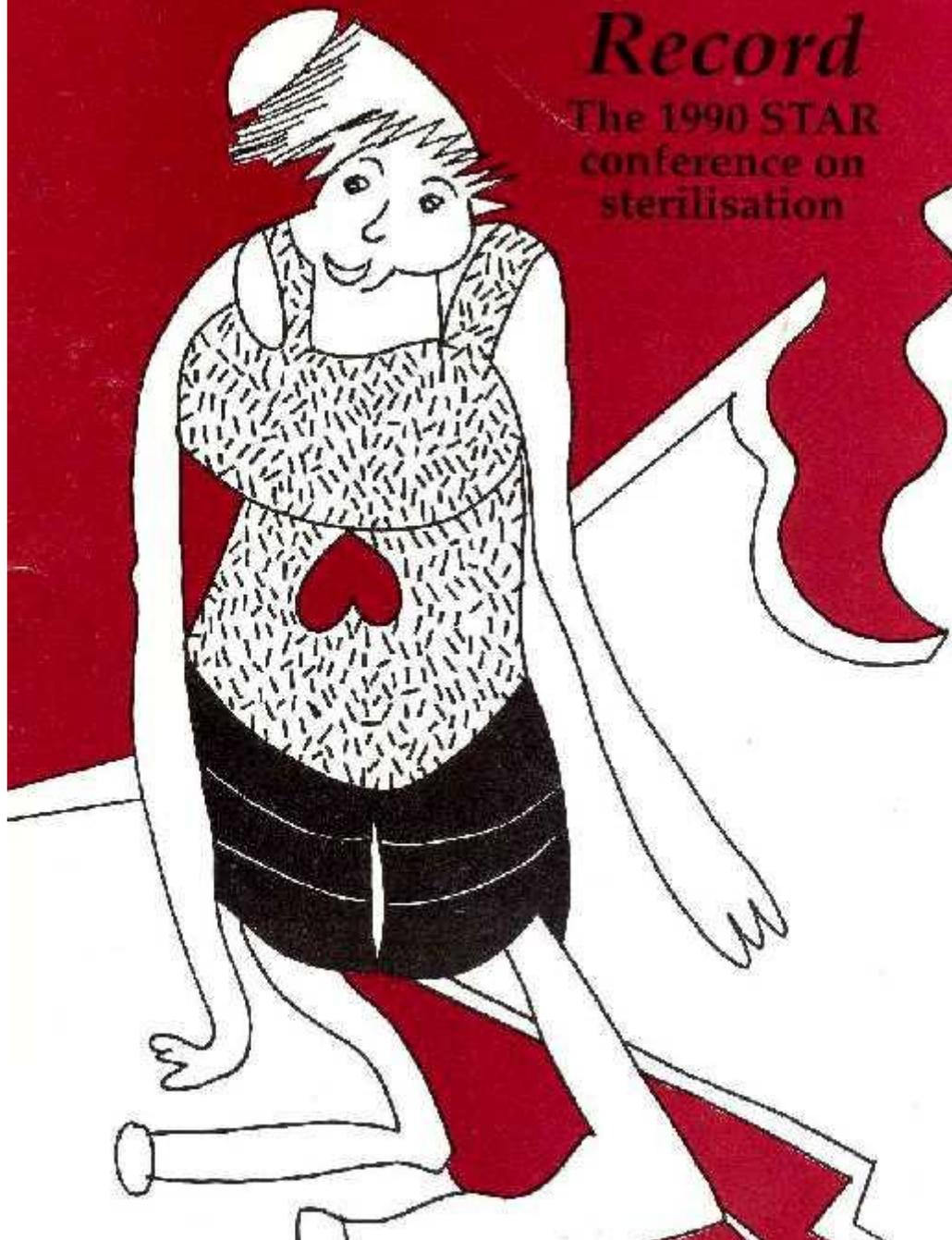


On The Record - A Report on the 1990 STAR Conference on Sterilisation: 'My Body, My Mind, My Choice'

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On the Record

The 1990 STAR
conference on
sterilisation



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About this Report

It is long.

It is complex.

There is a lot of technical information in it, and parts may not be completely accessible.

The recommendations are clear.

The statements from women with intellectual disabilities are strong and demand notice and action.

STAR will address this report with a project to follow up the recommendations with women with intellectual disabilities and their carers.

STAR welcomes comments on this report.

Fiona Strahan STAR 1991

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STAR has now got a grant from the Reichstein Foundation and Myer Trust to follow up the recommendations from this report - so don't put it in the filing cabinet, because it will be out again in the very near future.

Why the Conference

Sterilisation of girls and women with intellectual disabilities has always been contentious as it raises issues such as womanhood (being an adult, not an eternal child), sexuality, menstruation, pregnancy, parenting and rape.

It questions our ability to enable women to be equal and to be treated with dignity, respect and confidentiality.

It is contentious because it is also about power. Power that professionals such as doctors, lawyers, workers in services and parents have in influencing or making very serious decisions, that most women have power over.

Sterilisation is contentious as it challenges our society's ability to give women with intellectual disabilities all their rights as equal citizens.

It highlights the need for human relations education and training. It also highlights the need for access to health services and resources, and the need for adequate support services.

Since 1988 sterilisation has had significant media profile. Discussion within advocacy groups such as STAR and Reinforce had taken place prior to this, however the need to become more active was highlighted as decisions became more varied. The media was responding to Family Court cases considering hysterectomies for young girls with severe intellectual disabilities.

The momentum provided by these Court cases, enquiries from STAR members and questions such as *"What does STAR think?"*, *"What is STAR going to do?"*, *"We are considering a hysterectomy for our daughter, where should we go?"* motivated STAR to begin to address the issue.

Initially we sorted through the information we already had and we began to have a look at what the Family Courts had said in Australia and elsewhere in the world. STAR began to formulate its own position.

It is important to look at what the Courts have said regarding young girls with intellectual disabilities having hysterectomies to prevent menstruation, which they were seen not to be able to manage.

The issue taken to the Family Court was about consent and who had the right to make such a decision, parents or the court.

1989 Sydney, Family Court Re: Teenager.....

The Court held it could not usurp the power of parents when it appeared that they'd done everything that was expected of them as thoughtful, loving and caring parents. Justice Cook felt that the decision was not one for the Court to make but a decision within the power of the parents. He stated that only in exceptional circumstances should a Court, if asked, override the decision of the parents about sterilisation.

"To hold otherwise would bring about serious damage to the role and functions of parents".

Justice Cook concluded by being highly critical of the fact that the case came before the Court in the first place.

1989 Melbourne, Family Court Re: Jane.....

"If a procedure has a major aim of non-therapeutic purpose, then the Court's consent should be obtained. Parental consent is insufficient where a medical procedure involves interference with a basic human right, such as a person's right to procreate, unless it is clear that the interference is occasioned by some medical condition which requires treatment".

Chief Justice Nicholson rejected Justice Cook's (Sydney Family Court) views about the power of parents to decide about sterilisation. He felt *"parents cannot be expected to view the matter dispassionately or impartially because they themselves are so intimately involved with problems presented to them by reason of the care of the child in question"*.

1990 Brisbane, Family Court.....

"There is no point in the child going through the problems associated with menstruation if she is not ever to bear children"....."The organ to be removed from the child will not deprive her of any benefit."

Clearly the Judges differ dramatically on how they view the rights and capacities of women with intellectual disabilities. Following the increase in expectations for STAR to provide policy and program guidance, we identified that a conference on the issues would address the following needs:

- To find out what women with intellectual disabilities think;
- To challenge existing stereotypes which continue to restrict women with intellectual disabilities, e.g: "she is unable to look after herself", "she will be unable to manage her menstruation", "she must not have children", "this will stop her getting pregnant if she gets raped"
- Need for women with intellectual disabilities to have information about their choices and to be active in their discussion and promotion;
- Need to involve parents, family members, advocates, community residential workers, doctors, women's health practitioners in the debate and ensuing action;
- Need to identify how to deal with informed consent with women whose disability prevents them from doing so;
- To widen the context in which the issue is discussed to include Rights, Sexuality, Health, Ethics and the Law

What Did We Want to Happen?

We wanted:

- To enable women with intellectual disabilities to talk about their experiences and expectations;
- To identify the ideal processes required to enable a woman with an intellectual disability to decide that sterilisation is the best option;
- To provide people with a valuable framework of how to deal with the issue;
- To identify all the players in the issue and their potential contribution and bring them together to encourage and promote communication and understanding regarding the complexity of the issues;
- To identify who is responsible for decision making;
- To enable parents, families and other caregivers to discuss their fears and anxieties;
- To identify gaps in the information, education and support services;
- To present the existing options and their pro's and con's.

How the Conference was Organised

The first thing was to collect information: this was an extensive process due to the amount of information. We then wrote an issues paper "Sterilisation: A Choice Not an Expectation".

The second thing was to talk to people. When we contacted women with disabilities in STAR, AMIDA, Reinforce, People First and Janefield and started talking to them, the stories and the experiences of women began to pour in. Women with intellectual disabilities began to say what they'd like to have happen on the issues, and what they saw to be the major problems.

Many of the parents who we spoke to said that they needed more information about options available, where to go for advice and about what was 'right'. We also talked to the people who worked on the issues. Many came forward with ideas, information and the willingness to get involved. Once we began to talk about the issues, other people who had also been thinking, talking and working on them, became involved.

The third thing was to act. We decided on a conference for women with intellectual disabilities, parents and workers. We had to have some money. In three weeks we had a submission with the Victorian Women's Trust.

The fourth thing was to get a group of people together to organise it. The first meeting was attended by five women with intellectual disabilities and a number of support workers. We had a core group of five women who attended regularly; other women due to many commitments attended when they were free. Many of the women consumers were active and prominent in self-advocacy groups, accommodation services and support groups all of which required many meetings. At times the sterilization working group became, 'not another meeting'. We spent a lot of time talking at the meetings about personal experiences, clearing up misconceptions on the many issues relating to sterilization and talking about the similarities of women experiences.

The main task of the group was to design a conference which reflected and responded to the experiences of women with intellectual disabilities. What's more we wanted the conference to be accessible to women with intellectual disabilities.

After many different models we came up with the idea of two pre-conference sessions which were looking at 'What is Sterilization?'. These were to enable women consumers and their mothers or female carers to prepare for the conference.

This would be followed by a two day conference. The first day would be for women consumers and their female support people only and the second day would be open with special encouragement to parents, doctors and lawyers.

STAR was inundated with requests to attend the two pre-conference days. We could have run one every second Saturday for six months. However our facilitator Felicity Wiseman was already acting well above and beyond the call of duty. We chose to keep the group small as this was a criteria for accessibility.

The women who came had very different levels of understanding and degree of disability. "She won't understand any of this", was a common presumption. What we do know is that we can't know what someone with a significant degree of disability absorbs.

We had no expectation that anyone would come away from these days with a complete understanding of the issues, but certain experiences were offered. An opportunity to be with a group of other women in a friendly environment. To hear about and talk about our bodies. To feel and hold against us, rubber life size models of our uterus and ovaries.

In both groups participants drew their bodies and where they thought their uterus and ovaries were in relation to the rest of their bodies. This was a particularly successful undertaking as many women began to understand what 'bits' of their bodies did what, and then what options were available to 'stop periods' or 'stop babies'.

For many of the participants it was the first time that they had ever come together to talk and to learn more about their bodies. Lack of information, misinformation and out of date information about sexuality, contraception and menstruation was a common experience to all women participating, not only women with intellectual disabilities!

Women with intellectual disabilities and their parents are vulnerable to the extreme lack of information and misinformation. As one woman participant said, "at last it all makes sense, I can put all the bits of information together. Before I just had bits and pieces of information."

A number of the women consumers who attended the pre-conference sessions, did attend the conference, but not as many as we would have hoped. For some women their involvement was discouraged by others, as it was felt "they would not understand what was happening", "they would not get anything out of the conference", they would cause problems."

Attitudes such as these arose before and during the conference. It was at times difficult to let people see that firstly the conference was for women with intellectual disabilities and secondly, that not even the organising committee understood all the issues. We too were learning more and felt that people attending would experience and learn something positive.

"Things like this are not for people like her" was said. We responded with "Enable her to come, support her participation and see what happens". We had sufficient people present to support the participation of women with a greater degree of disability. This was done.

Making the Conference Accessible

We wanted a format where women with intellectual disabilities did not get left out of the process. The group decided that the conference would focus on three workshop areas, these were medical techniques, women's health including sexuality, and legal issues.

Women consumers felt that conferences that had speakers followed by questions followed by more speakers and workshops were not for them.

The format consisted of three groups of people who would attend three workshops together. This meant we would have to find presenters who were willing to run a workshop three times. We were lucky enough to do so. Each group had a contact person who was a consumer who had been involved in the conference working party. Their role was to act as a focal point for other women consumers in the groups. They had also met previously with the chair people and were familiar with the note-takers.

In the final session of the first day we revised the program for the second day and we gave an overview of the topics for the workshops. Women were then given an opportunity to think of questions they may want to ask and these were written on cards. The cards were then held by the chairperson of the group, who handed them out the next day. This enabled the chairperson to say "Freida has a question about that". Each group had a chairperson who met and worked with the group from the first day of the conference. Their role was to ensure that debate and discussion was not dominated by anyone person, that language was kept clear and jargon to a minimum, that women consumers participated in the discussion. They also acted as resource people in helping people move around the conference setting.

A note-taker was also assigned to each group. Each group was then allocated a colour. This was on their name tag and colour was used to indicate rooms that people were to go to next; This we felt would address the literacy obstacles. Chairpeople were given the names of those who were consumers, their support people and professionals and where they came from. This was important information for the Chairpeople so as to enable fair participation. Our definition of support people were people whose role was to enable consumers to participate; they were parents, workers and friends.

In organising the groups we spread people from the same organisations across the groups except when consumers requested that they stay together. Profession types were spread across the groups so each group had at least one doctor, hospital social worker, and so on. We prepared information folders for each workshop. This required much searching, collating, photocopying, which was undertaken by Frances Calleri, a student on placement and other members of the working group.

The folders were in hot demand during the conference and for some weeks after. Information came from the women's information centres throughout Australia, disability rights groups, the Family Planning Association, legal centres, family education units, doctors, government departments, community based organisations, and individuals. Some international sources were used.

Attitudes on Sterilisation

The following are extracts from the issues paper '*Sterilisation: A Choice Not an Expectation*' by STAR.

Between 1909 - 1929, 6,000 operations were carried out in the U.S.A. to breed out the 'unfit'. In Sonoma State Home all patients were sterilised before leaving the home to go out into ordinary life:*the first step is to ensure that they shall not be allowed to perpetuate their kind*".

Has this attitude changed? Incorrect information concerning women with intellectual disability having disabled babies, is still the basis on which many promote sterilisation. Sterilisation has also been promoted in the following manner: *"I fear that one day she will get raped and if she is sterilised then we don't have to worry that she'll get pregnant"*.

In the 90's sterilisation has been promoted for solving pregnancy as a result of rape and more recently for protecting a worker from coming into contact with possible HIV positive menstrual blood. These views are most extreme, unrealistic and most definitely dis-empowering. They ignore the many preventative steps which may be taken by, and with women with intellectual disabilities. They ignore the equal status and rights of women with intellectual disabilities.

In 1981 the NSW Anti-Discrimination Board noted with concern that:

"sterilisations are being performed on intellectually disabled people without their consent or even their knowledge. Such action constitutes a serious denial of their civil rights and appears to be carried out in disregard for the considerable psychological stress that can be caused. The A.D. Board consider sterilization acceptable only when those who have the mental capacity to give consent, make the choice themselves on the basis of alternative methods of birth control and the consequences of sterilization having been explained."

At this point the Board does little to address the issues of consent from girls or women with severe intellectual disability for non-therapeutic operations. This may be because it has little power in this area, or because the answer is unclear.

At STAR's conference women talked about the following experiences:

"I went to hospital and instead of having my appendix out, I had a tubal ligation."

"After trying to have a baby for a long time I finally found out I had been sterilised when I was 14 living in an institution."

"I was being pressured into having an abortion."

Women had also been given lots of reasons on why sterilisation was good for them:

- she would not have to be informed about menstruation or learn about personal hygiene;

- she would not have to experience the discomfort and inconvenience of monthly periods;
- she would have no danger of pregnancy with all its accompanying pain and trauma;
- she would have no need for an abortion;
- time would not have to be wasted on sex education;
- women with intellectual disability are unable to bring up children;
- her child wouldn't have normal parents;
- if she gets raped there'd be no worries about pregnancy;
- her child may also have a disability.

In viewing the Court cases and listening to the experiences of women the following issues are highlighted:

- psychological and physical side effects of early hysterectomy not extensively documented.
- no safeguards for girls under 18 in Victoria against unnecessary sterilisations unless it comes to the attention of the Court.
- lack of understanding by doctors, parents, service providers and the law of less dramatic and less permanent options available to women.
- negative attitudes towards the sexuality and reproductive capacity of girls and women with intellectual disabilities.
- lack of education, resources, information and support on menstrual management, contraception and child care for girls and women with intellectual disabilities.
- lack of understanding of and commitment to, the rights of girls and women with intellectual disability.
- inadequate training of medical and legal professions about the rights of girls and women with intellectual disabilities.

Sterilisation, be it for contraception or menstrual management, appears to be used too unquestioningly with women and girls with intellectual disabilities.

STAR on Sterilisation Issues

STAR has been proactive on the issues of sterilisation over the last 15 years. This has enabled STAR to develop a perspective which is responsive to the needs and expectations of women with intellectual disabilities. An important part of this development took place during the late 1970's when STAR corresponded with individuals and organisations at a national and international level.

The sharing of information and discussion of major issues and developments was intensified as people worked through the issues and built up a knowledge of ethics and procedures. The following are extracts from correspondence conducted during this time.

In 1976 in London the Council on Mentally Handicapped (CMH) said: *"as a matter of principle, no child under 16 should be sterilised except when this is a by product of a life-saving procedure. CMH believes that there is no justification for any operation of such seriousness at such an early age. CMH believes no adult should be sterilised against their will."*

Sweden 1976: *"involuntary sterilisation is now illegal and the operation can only be performed with the consent of the individual concerned."*

In a letter from the Royal College of Obstetricians and Gynaecologists Victoria State Committee in 1979:

"It is quite apparent that this problem (sterilisation procedures in the mentally retarded patient) is extremely complex. It was considered that the question of sterilisation of the mentally retarded patient should remain the responsibility of the individual practitioner rather than the prerogative of an independent board, and that the decision to sterilise such a patient should be taken after appropriate consultation with the person or persons responsible for the patient."

In 1985 STAR prepared a paper identifying key issues in the debate. The paper included the following statements:

If one accepts the broad statement of the rights of people with disabilities, then one must also accept their rights to enter into sexual relationships, to be parents and, consequently, their right to be supported in carrying out these roles.

This means that any blanket statement that people with disabilities should be sterilised is inconsistent with the principles of social justice promoted by disability activists.

One must rather pose the question: What supports are required to make it possible for people with disabilities to be as informed and competent in sexual relationships and in the responsibilities of parenthood as are other members of the community?

This is a complex and very vexed question which will depend upon the nature and severity of the individual's disability. For example, one person with a disability may be quite capable of being a competent parent with only a little tuition on parenting skills, while another might require regular drop-in support, while yet another might need, in the interests of the child and of herself, to consider options such as foster care and adoption.

Summary

The main points to consider in debating the issue of the sterilisation of people with disabilities are, therefore:

- The rights of people with disabilities and their status as human beings.
- The rights and capacities of people with disabilities to enter into sexual relationships.

- The availability of and need for services which support people with disabilities on issues related to sexuality.
- The rights and capacities of people with disabilities to be parents.
- The supports and services available to people with disabilities who become parents.
- The capacity of a person with a disability to give informed consent to sterilisation.
- Legal provisions available for decisions about sterilisation to be made on behalf of someone who is unable to do so independently.

Through consideration of these points, it becomes apparent that the question 'Should people with disabilities be sterilised?' cannot be answered with a simple 'yes' or 'no'. It is rather a matter of, on the one hand, advocating for a broader range of support services so that sterilisation is not the only option open to a person with a disability and, on the other hand, defining the procedures and circumstances under which a sterilisation may be performed on a person who has a disability.

In 1990 STAR stated that all women with intellectual disabilities had the right to control their own bodies.

STAR is concerned with the ease with which hysterectomy and tubal ligation are promoted as the solutions to menstrual management and contraception for women with intellectual disabilities. Existing and viable options are often not explored and parents and other caregivers are not made aware of these, or are discouraged from understanding their effectiveness.

Parents and other caregivers need resourcing and support if they are the ones to assist in managing a woman's menstrual cycle.

The STAR Board supports Justice Nicholson's view that parental consent is insufficient where a medical procedure involves interference with a basic human right, such as a person's right to procreate, unless it is clear that the interference is occasioned by some medical condition which requires treatment.

What Women with Intellectual Disabilities Brought to the Conference

At the conference women with intellectual disabilities made strong statements concerning their lives and the issues of sterilisation.

In her speech opening the conference, Josie Atkinson made the following statement:

"I know of other women who have been forced sterilised also. The disabled netball has a state team you could only play in if you have been sterilised. I couldn't play because I hadn't been sterilised. I think that is discrimination and blackmail as well going on there. At the STAR ,conference I hope to get resolutions to what is happening. I find this is a very touching personal thing. I feel it is important to me and to other women. I have written this speech because it is something I would like to get across to other people. But I hope other women come away with a positive outlook on the issue of sterilisation.

Because it is a real reality to life situations. I don't know what other people think but it is the choice of the person it's their body. Other people shouldn't make decisions for them. Cause after all this is what the conference is all about. And it is really a top priority in the future as well. People with disabilities have the same rights as anyone else. I think there should be an Act that should go through Parliament, it must be a Sterilisation Act in the State of Victoria that stops girls and women with intellectual disabilities being sterilised. There was a case in England where an intellectually disabled woman was 17 years of age. The House of Lords had a case in Court and the parents and the law made her have a sterilisation. Reinforce sent a telegram trying to have it stopped. We wrote to the Prime Minister Mrs. Margaret Thatcher. But it went ahead as planned. It was in the Sun Newspaper."

Why Women Came and What They Wanted:

"learn how my body works, meet people and talk about sex."

"get ideas on relationships and how they work."

"about needles and pregnancy. How it works. How hospitals work."

"learn more before having an operation."

"to make decisions and choices that are right for me."

"I want to find out about advantages and disadvantages of contraceptives."

"Some people think: people with disabilities shouldn't have sex because it's not the right time and that discussing sex brings up things they don't need to know."

"We were not allowed to join things (sport) unless we were sterilised."

"We are not well informed about what periods are and we want to talk about cramps, headaches and embarrassment."

"What are the long term side effects of sterilisation?"

"What are my rights if I'm forced to have sex?"

"What can I do if I'm forced to have sex?"

"What is a 'heavy' period and how heavy is heavy?"

"What happens if you don't get your period?"

"What do you do when you feel 'yuck' before your period?"

What Women Said by the End of the First Day:

"We want to know how many women have been sterilised."

"We want information about relationships and having babies."

"We want to know more about our health."

"As parents we want to know, ways to deal with menstrual management."

For many of the women at the conference this was to be the first time that they were able to speak freely about their bodies and their experiences, both positive and negative, relating to issues of sex, contraception, menstrual management and sterilisation.

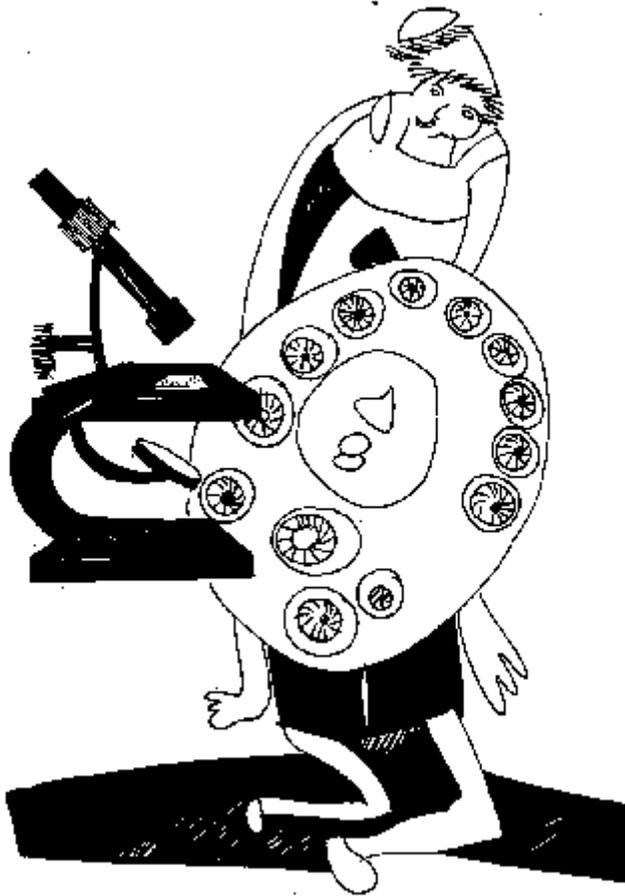
It was also the first time that many of the women who came as support people realised that they too had found accurate and correct information about their bodies difficult to get. They too had been misinformed or, insufficiently informed, about their bodies.

As a result women with disabilities saw that their friends, support workers and parents were not 'all knowing'. Some workers talked about how this awareness resulted in a shift in the power of their relationships - they became more equal. It was realised that we weren't discussing issues peculiar to a woman with an intellectual disability, but rather issues common to all women.

A Parent's View - Hope Black, a Conference Participant

As a parent of a twenty-four year old Down Syndrome daughter I was vitally concerned with the issues raised at the conference My Body, My Mind, My Choice. When our daughter was eight, a day training centre worker told me that I should arrange for her to have a hysterectomy as it was a must for all intellectually disabled girls. Having some knowledge of human physiology and hormone balance her father and I adopted a wait and see approach depending on what problems developed when she began to menstruate. None did - with adequate instruction and supervision at first - she manages her personal hygiene quite satisfactorily. As parents the other issue that concerns us is her right to express her sexuality. She enjoys the company of the opposite sex and would like to have a special male friend. She does not lack male companionship as there are male clients in the CRU where she lives

during the week. She also has male social contact at weekends. If, or when a special male appears then will be the time for them, with our help, to decide the future of their relationship. This issue immediately brings up the possibility of sexual activity and pregnancy. With education and counselling I am quite sure that many intellectually disabled women are quite capable of understanding the need for restraint in their contacts with the opposite sex. Hysterectomy or even a less drastic form of sterilisation is likely to be a very traumatic experience if there is not some previous explanation of procedures and familiarisation with hospital and staff. So why suggest pregnancy and child birth is too traumatic an experience to allow them. As far as being able to care for a child - there are many and varied abilities exhibited by members of the community at large. As for rape, it is continually occurring in the community and women don't go round wearing a notice 'I have had a hysterectomy' and even if they did I am sure it would not deter the rapist. Yes the severely handicapped may have difficulty but with them many of the issues don't arise. Is menstrual flow any more of a problem than their incontinence? This degree of disability requires twenty four hour supervision anyway. In this letter I am being deliberately provocative and; am sure many parents will take me up on some or all of the points I have raised. But let us be objective as well as caring and protective. Our disabled offspring have disabilities that limit them but apart from these specific disabilities they are human beings with all that the term implies. They have the same physiology and body functions with the same basic requirements, they have the ability to love, care, learn and respond to their environment. In a caring supportive community let us help them lead fulfilling lives.



"The outside is obvious - somewhere in the middle of my body something happens - feelings, ideas, changes. No clear answer for this."

Women's Health

Some women with intellectual disabilities find it harder to manage the sexual and physical aspects of being a woman, especially when they cannot openly discuss experiences relating to periods, sexuality and contraceptives.

During Day One of the Conference it was important to establish a basic understanding of anatomical aspects relating to sexuality and menstruation. For instance which parts of the body did what, which part was taken away or cut when a woman was sterilised, where the uterus was and what the vagina looks like. The information needed was provided in various forms. For some, this information was all new. For others it came as consolidation to fragmented information gathered over the years.

Women sat in groups, talked about, touched and looked at rubber reproductions of male and female reproductive and sexual organs. Anatomically correct dolls and various forms of contraception were passed around. In effect this session acted as a precursor to further understanding, and the discussion which was to follow on Day Two.

Sexuality

"Many disabled people feel cut off from Society, outcasts from ordinary experiences, protected from the darker side of life, mixing with only those similarly handicapped. And these feelings are reinforced when parents and others who care for them imply that sex is not for them, and do everything to avoid arousing emotional and sexual urges. "They don't have the same feelings as other people, and anyway marriage is out of the question, so what's the point?" This attitude is based on the belief that what you do not have you do not miss - which may apply to caviar and smoked salmon, but not to sex. Apart from the fact that sex is undeniably good for you - this proposition ignores the emphasis that society is currently placing on it through advertising, T.V., books and magazines; which constantly thrust it at us with the certain intent of arousing and titillating."

(Entitled to Love: The Sexual and Emotional Needs of the Handicapped, Wendy Greengross, Malaby Press Ltd., London, 1976)

Our society has restrictive views towards women and the control they have over their own bodies. The message put out is that:

- We should have babies.
- We attract rape or asked for it or we like it.
- We go nutty when we bleed.
- We are either over-sexed or frigid.

Women with intellectual disabilities have said that they have encountered attitudes such as:

- We are asexual.
- Don't have feelings.

- Don't understand (and can't) our own bodies.
- Can't take responsibility for our bodies or our lives.
- Must not reproduce.
- Can't/mustn't have relationships.
- Get hysterical with blood.
- Can't manage menstruation.
- Will get raped.
- Attract awful types (our fault).

Some of the questions and thoughts that arose during group discussion were:

"Some parents didn't explain about sex."

"Sexuality is something that is with us from the day we are born until the day we die. It is with all of us!"

"Why don't men take responsibility for contraception and/or sterilisation?"

"I have missed out on having a baby. What can I do now?"

"How can I make sex fun?"

"How can I relax when I'm having sex?"

"How can I have sex when the staff don't like it?"

"In (my institution) you were not allowed to be with a man. You got into trouble. It's not right."

"Can women have I.U.D.'s? What are the side effects?"

"I think education about sexuality should be given much higher priority its the right of everybody to know as much as possible!"

"Condoms - do you buy them at a chemist?"

"What will the workshops be about?"

"I want to know about babies, foster care and fathers."

"I have a boyfriend and I want to know more about our relationship."

"I want to know about private parts, more about my body and how it works."

"I want to learn about private parts and safe sex."

"We want to challenge attitudes and stereotypes that women with intellectual disabilities are either asexual or promiscuous."

"Sexuality needs to be acknowledged in the policies of Community Services Victoria and other agencies. Women are too vulnerable to the personal attitudes and values of staff."

In 1987 ACROD held a seminar: 'Embracing Sexuality', the following points reflect on the above statements.

"It is a myth that people with disabilities are asexual and it is also a myth that they are over-sexed - people with disabilities may suppress their sexuality because of the way they are interacted with, because they are regarded as perpetual children (or as one participant expressed it - a perpetual Peter Pan).

There are many women who, throughout their early lives, were regarded as asexual and constantly reminded that they should not, could not and indeed would not enjoy a sexual experience and for whom this dire forecast became self fulfilling prophecy. Alternatively, people with disabilities may appear over-sexed because they have nowhere to hide or be private. Constant supervision and necessary nursing and medical intervention leaves no room for privacy. Many parents fear that their children maybe vulnerable to exploitation which often leads to denial of sexuality and over-protection. This in turn can lead to lack of opportunity to take normal sexual risks in early adulthood. This lack of experience in low risk choices may adversely affect later judgements.

It must be reiterated that what we are talking about when we discuss sex and disability is not how to have intercourse in a wheelchair or how to flirt in an invalid car. It is the wider approach of integrity and humanity, and the questions of how the disabled person sees herself and how sex can enrich her life and enrich society at the same time. That is the extra dimension.

It is true that with intellectual disabilities women are more likely to be sexually used than more sophisticated, assertive non-disabled women. However, it must be admitted that protecting a woman from pregnancy is not the same as protecting her from exploitation. A sterile woman is just as vulnerable to exploitation - perhaps more so because there will be no pregnancy to "tell" that she is being sexually used. The alternative is to develop close communication and to teach women with intellectual disabilities how to protect themselves.

Sexuality is an integral part of our selfhood. It involves more than just being anatomically and genetically female or male, and it is not defined just by one's sexual acts. It influences our perceptions, attitudes and behaviours in relation to other individuals and to society. From the beginning until the end of our lives our sexuality intrinsically affects all aspects of our existence; it affects the way we think and feel, what we do and who we are."

At the STAR Conference Women Said That:

"If we are serious about integration and de-institutionalisation; sexual, reproductive and parenting rights have to be addressed."

"Issues relating to sterilisation or hysterectomy for girls and Women with intellectual disability are often seen as 'too hot' or 'too uncomfortable' to deal with, as to do so means we must talk about sexuality, reproductive capacities and rights."

"Women in institutions don't have many options regarding their bodies and sexuality."

"People don't tell us about sex."

"There is a lack of training, information and resources about sexuality for women."

"How can we educate the community (especially in country areas) about sexuality for women?"

"What can be done state-wide to address the lack of education about sexuality?"

"For years parents and professionals have shied away from the issue of sex education for people with an intellectual disability because of the conflicting emotions, moral perspectives and philosophies."

"Many adults now living in the community have not had the benefits of learning about human relationships and sexuality at an appropriate age".

"Organisations need to regard their clients as fundamentally no different from others".

"According to Craft (1988) people with an intellectual disability have four main rights. Firstly, they have a right to know about themselves, their bodies, their emotions and appropriate social behaviour. Secondly, they have a right to a humane dignified environment which includes privacy. Thirdly, they have a right to be protected from sexual attitudes of individual care givers; finally they have a right to make relationships."

(Models for Change - The Experience of Intellectual Handicap Services, Department of Family Services Qld. Winter '89 Community Bulletin).

The whole area of sexuality, marriage and parenting for people with an intellectual disability raises questions for the community, care givers and for people with disabilities themselves. These concerns will not 'go away' instead they need to be faced in an open and honest manner to allow the person with a disability to acknowledge his or her sexual needs and to deal with those needs in ways which enhances self esteem and promotes the understanding of responsibilities and options.

Menstruation

At the conference women said the following about menstruation:

"We should have information about 'bleeding'."

"It seems that periods are sometimes suppressed for the convenience of care givers, support persons and services."

"There is a glaring lack of in-home assistance and support for families supporting a woman learning about menstruation."

"Having your period gives a context for others to decide why you have to be on contraceptives."

"The first period is often a shock to all young women."

"All women get their period at different ages-perhaps education services should be made aware of young women getting their periods when 10 years old."

"Information on menstruation can't be difficult for all women to take in. Until a woman bleeds it may be difficult to explain to her what is going to happen."

"Some women were frightened because they didn't know where the bleeding was coming from."

"Women have often been scared and have cried because they didn't know what a period was."

"It is important to talk about bleeding as women often don't know about their bodies, i.e., there are 3 holes and which one do you bleed from?"

"Good to tell others that a period is natural and will happen every month."

"All women have a right to know about their bodies - so we need to look to who should do this 'giving of information'."

"Where should you learn about periods? At school? Somewhere independent? Loving, informed mothers, sisters, or friends?"

"One woman went to the library and found out about what was happening."

"Women are often disadvantaged because they don't have other women friends to talk to, i.e., if they are in a Community Residential Unit or an institution."

"Many women don't have contact with their parents because they are in community residential units or institutions."

"Parents are often overloaded if they have their daughter at home - so we need to create other viable resources."

"There are some education information services available where families can go and get information."

"There is a video which is called: 'Janet's Got Her Period' from The Social Biology Resources Centre which provides menstrual management training."

"As a mother, it is hard when you have explained (about menstruation) and the young girl doesn't want to wear pads. Persevere and perhaps let them change pads and sheets and wash sheets!"

"Some mothers are often embarrassed to tell their children what is happening."

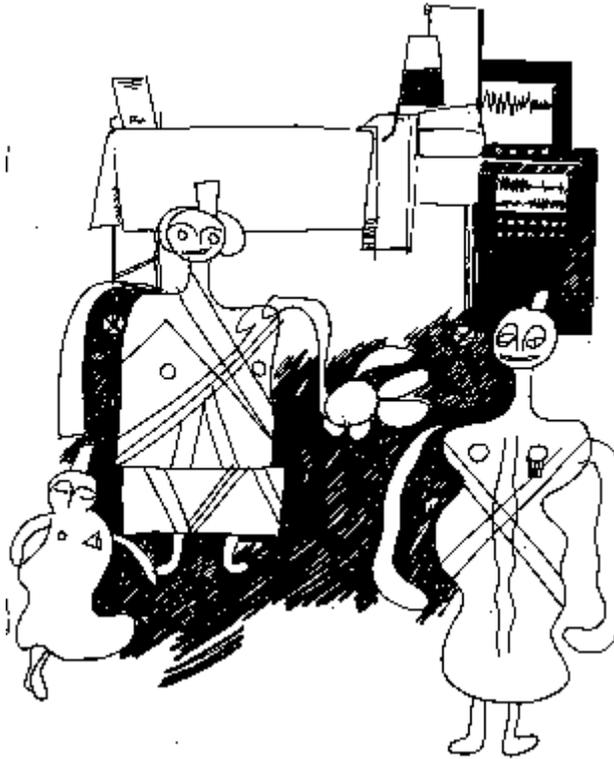
"It is good for women to go to women's groups that discuss sexuality and health issues."

"It is important for all women to share information with each other."

"Women need access to support groups and people to talk to. Language needs to be clear."

"Menstruation should not be a 'rights' or 'privileges' issue - it is something common to all women and affirms their womanhood. It need not be a crisis, indeed it is a natural physiological occurrence in all women and should not be viewed as a disability problem. In order for our daughters to be prepared for adulthood, we need to offer our encouragement and support often overcoming unfounded fears. Accept the reality that our daughters require the same opportunities for love, sex, self expression and development as ourselves. It is especially important that we are aware that everyone has sexual needs which must be respected."

(Helen Brown Management of Menstruation Kit (NSW) Family Education Unit).



Medical technology - no patient in bed - technology process takes priority.

Medical Techniques

In the Medical Techniques section we have included information from the Monash Medical Centre and Women's Information Health and Resource Centre. This information was provided in the kits which were presented at the conference.

Sterilisation

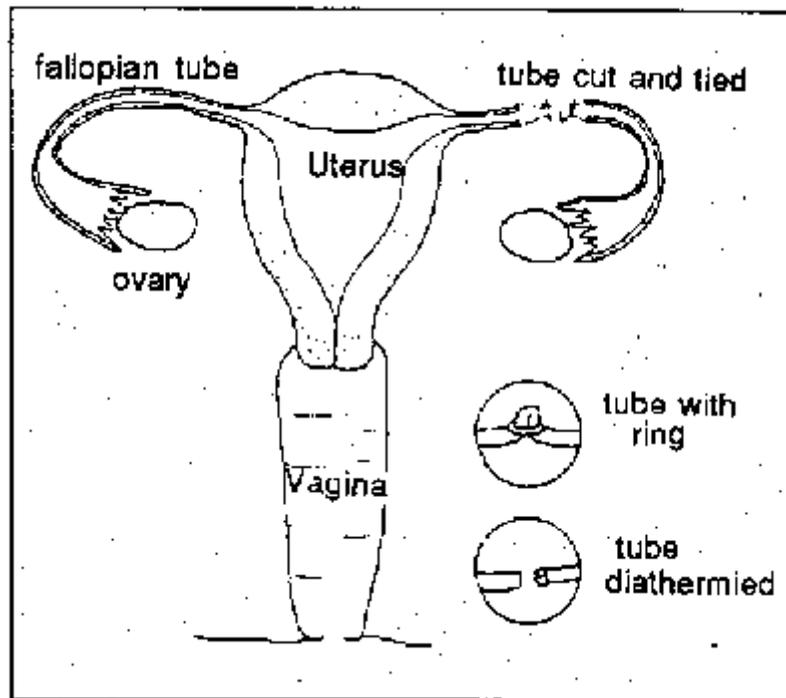
What is Sterilisation?

Sterilisation is an operation performed on women and men to make them incapable of having children. Other forms of birth control are less permanent. It is much safer, cheaper and simpler for a man to have a vasectomy than it is for a woman to have a tubal ligation. Vasectomy is a more reversible procedure than tubal ligation, this means the man stands a good chance of regaining his fertility later on if he has the reversal operation; a woman does not.

Who Gets Sterilised?

Tubal ligation is a widely used method of contraception. Some women are being sterilised without their knowledge or consent as a way of 'controlling' the population of some countries. Tubal ligation is often misused. Some doctors and some male partners often pressure women at a vulnerable time, e.g. while they are in labour or immediately after giving birth or having an abortion. In many situations, women tend to trust the doctor's opinion rather than following their own feelings. In other cases, particularly with white anglo-saxon women, there may be difficulty in persuading a doctor to perform the tubal ligation, especially if they are young or single, or have few or no children at all.

Being forced to have a sterilisation, or being prevented from having an abortion keeps women from having free choices and control over their own bodies.



What Happens to You with Tubal Ligation?

There are several tubal ligation operations. In all of them, a section of the woman's fallopian tube is closed off. This can be done by:

1. Cutting out a section of the tube and tying the cords with surgical thread;
2. Leaving the tubes intact and placing rings or clips over them;
3. Sealing them with electrical current to block the passage (diathermy).

The closing of the tube prevents the male sperm from travelling to meet the female egg (ovum), therefore making pregnancy impossible. This type of sterilisation is said not to affect a woman's hormone secretions, ovaries, uterus, or her vagina. Her menstrual cycle continues. An egg ripens in and bursts out of an ovary every month, but stops part way down the tube, disintegrates and is absorbed by the body. As with any operation there is a risk for the individual who is operated on. If too much of the discussion focuses on sexual response and procedure, though these are important, the information on risk may be under-emphasised. Doctors may be more likely to emphasise the positives and avoid the negatives.

Laparoscopic Sterilisation

This is the most common procedure. A laparoscope is a long thin tube with a series of lenses running along it, and containing a channel through which other instruments may be passed to grasp, cut or burn tissues within the body. In this procedure, your abdomen is filled with carbon dioxide gas via a small needle, usually inserted above the pubic hair line. The muscular abdominal wall will thus balloon away from the uterus and tubes (so the procedure may not be suitable for women who have any old scar tissue or who are very overweight).

A small incision is made below your belly button and a metal tube (laparoscope) is inserted through the layers of fat and muscle. Through this hollow tube the doctor is able to see the entire pelvic area, and through another small hole above the pubic hair line is able to pick up each fallopian tube and either cauterise (burn) or place a ring or clip over the tube. The carbon dioxide gas is then allowed to escape through the larger tube. This procedure is usually done under general anaesthetic, but could be done under local anaesthetic in some circumstances. It usually requires an overnight stay in hospital.

Reversibility

It must be stressed that only a very small minority of women have been able to have children again after sterilisation. Rejoining of the fallopian tubes (reanastomosis) is simple in principle, but difficult in practice.

New micro surgical techniques have cut down on scar tissue, and pregnancy rates after reversal have climbed from around 30 to 60% of women accepted for reversal operations. This does not mean that 60% of women who've been sterilised could become pregnant after reversal, for doctors only operate on women whose fallopian tubes have not been too severely damaged by sterilisation, and who have no other problems that affect their fertility, or make child bearing a health risk.

Clip and ring sterilisations are the most potentially reversible procedures, and diathermy is the least. But this is also very dependent on the skill and experience of the doctor who originally did the sterilisation, and the doctor attempting the reversal.

One of the side effects associated with reversal is a higher incidence of pregnancy in the tube (ectopic pregnancy). The reversal operation is major surgery which takes some time to recover from and has no guarantee of success.

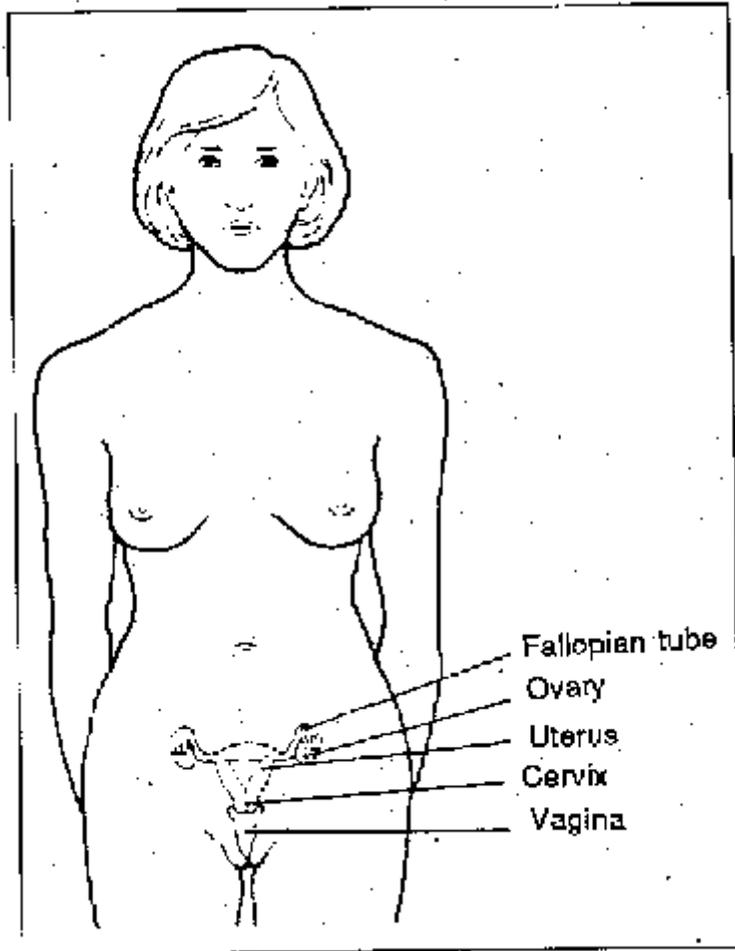
Hysterectomy - A Fashionable Trend

The rate at which hysterectomies are performed is extremely high. Figures released in June 1982 show that 40% of Australian women will have a hysterectomy before their natural menopause. This is three times higher than in comparable countries such as Sweden and Britain.

What is a Hysterectomy?

A hysterectomy is an operation for the removal of the uterus (womb). The uterus is quite small (about the size of a pear) so that the space that is left behind is quickly filled with the bowel. The operation may be performed in one of two ways.

1. Abdominal Hysterectomy: An incision is made low down in the abdominal wall several inches above the pubic bone. This is the common approach.
2. Vaginal Hysterectomy: This approach is less common and is usually done when there is a prolapse of the uterus (falling of the womb) and a hysterectomy has to be combined with repair to the walls of the vagina which have also fallen.



There are also four different types of hysterectomy.

1. Total Hysterectomy

A total hysterectomy means that all the uterus is removed but the ovaries are left. However, it is often thought that removal of the uterus, tubes and ovaries is a 'total hysterectomy'. This is not strictly true.

2. Sub-total Hysterectomy

This is not a common operation now but was performed more frequently in the past. It means a partial hysterectomy with the body of the uterus being removed but the cervix left in place. Ovaries are not removed.

3. Hysterectomy and Bilateral Salpingoophorectomy (i.e. removal of ovaries)

This means that the uterus and the ovaries are both removed. The production of oestrogen by the ovaries comes to a sudden stop. This surgical procedure results in an 'instant menopause'. The immediate symptoms can therefore be more severe than in a natural menopause.

4. Radical Hysterectomy

This means removal of uterus, fallopian tubes, ovaries, ligaments and lymph nodes. It is performed in some instances of cancer involving the cervix.

"It appears to us that in Victoria, as elsewhere, hysterectomies, tubal ligations and to a much lesser extent vasectomies have been used as an easy alternative to education and independence training. We do believe that parents and relatives of people with disability are frequently unable to come to terms with the disabled persons sexuality and their ability to make a balanced decision is consequently impaired."

(Cocks Report of the Minister's Committee on Rights and Protective Legislation for Intellectually Handicapped Persons).

When used for contraception and menstruation control both tubal ligation and hysterectomy are non-therapeutic operations. The body is not sick. In fact the onset of menstruation for a young women is the indication of a body acting in a normal and healthy way.

Transcervical Resection

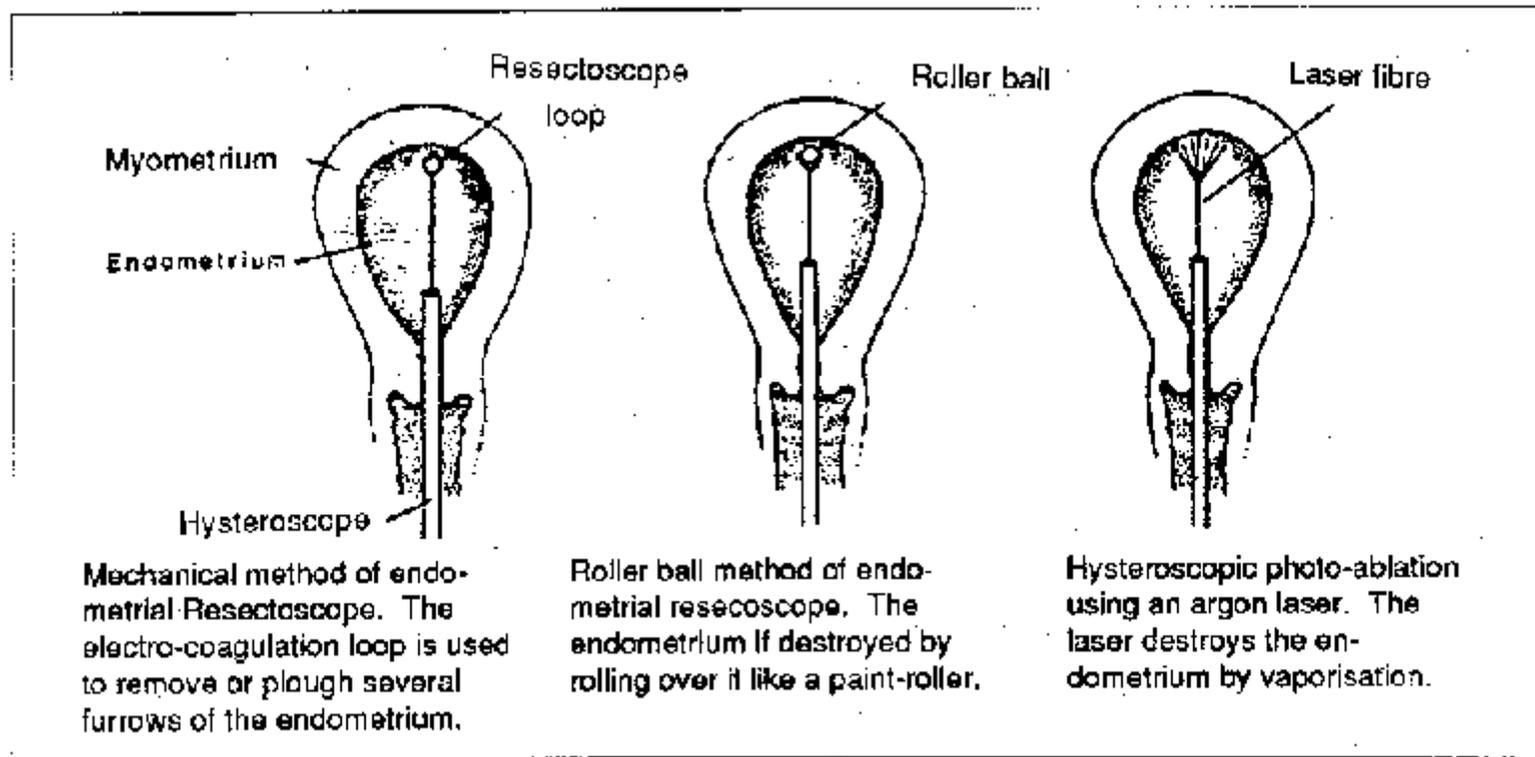
This is an alternative to hysterectomy. Using the hysteroscope to give visual access, an instrument called a resectoscope removes either the whole, or part of, the womb lining. A special fluid is introduced to distend the womb cavity for this operation. Complete resection - total removal- means there is a 50% chance of periods stopping completely; partial resection means periods return, although they will be lighter than before. When appropriate, the option for total or partial resection is offered.

Laser Treatment

This method of destroying the womb lining also uses a fluid to distend the womb cavity and to improve visibility before the laser is inserted. The 'Nd - YAG laser', as it's called, has a fibre tip which is moved over the womb surface to administer the laser beam. The procedure is usually carried out under general anaesthetic. Most patients have an overnight hospital stay but some hospitals are doing day surgery. Post-operative cramps for a day or two may be experienced. This procedure requires greater skill than the other two methods. It is also more expensive, and this is a disincentive for its use. So, though it is the longest established, it is unlikely to become as widely available as the other two methods.

Microwave Surgery

This is the latest procedure. Surgeons claim that it promises to be the best way to cure heavy bleeding, because it is the easiest method to perform and has the fewest risks and side effects. Its proper name is Radiofrequency Endometrial Ablation (RaFEA). RaFEA destroys the womb lining by using electromagnetic energy similar to that used in microwave ovens. A probe inserted in the womb generates the heat and is left in place for 20 minutes. The technique has been used in trials for about a year, but is now becoming more widely available. The desired results may not be instant. Periods may continue after treatment, though they are usually much lighter. In some cases they decrease gradually, in others they disappear completely.



Depo-Provera

Depo-Provera is the trade name for depomedroxy progesterone acetate (DMPA). This is a synthetic progestogen. Progestogen is the name given to a group of hormones which have similar actions in our bodies. Depomedroxy progesterone acetate is a chemical which is manufactured, so whilst it has actions like natural progestagens, it also has other effects.

In the injection of Depo-Provera there are very small crystals of DMPA suspended in water. When an injection is given, the DMPA is slowly released into the blood-stream over several months. The usual dose is 150 mg given every three months into either the upper arm or the buttocks. Every woman clears the drug from her blood stream at different rates. Because the purpose of the drug (when given as a contraceptive) is the prevention of pregnancy, dosage levels are chosen at a rather high level, so that no woman can clear it sufficiently to ovulate. This means that for most women, the dose is probably well in excess of that needed to provide contraception.

The main way Depo-Provera works as a contraceptive is to suppress ovulation, so that during the three months no eggs are released from the ovaries. The way it does this is not by directly affecting the ovaries. Instead, it acts on the hypothalamus and pituitary gland - two areas in the brain which play a major part in regulating and maintaining the balance of hormones in our bodies. Depo-Provera alters the release of two of the hormones made by the pituitary gland. It is the cyclical rhythm of the release of these two hormones which triggers ovulation, and also stimulates the ovaries to produce the two hormones oestrogen and progesterone. (The levels of these two hormones are lowered in someone who has been given Depo-Provera.) Depo-Provera also alters the lining of the womb (called the endometrium). This means that if ovulation and fertilisation did occur, a fertilised egg would not be able to attach itself to the endometrium and grow and receive nourishment during the early weeks of pregnancy.

The third way the Depo-Provera acts as a contraceptive is to alter the mucus secreted by the cervix (the neck of the womb). It becomes thicker and sperm are less able to get through the cervix into the uterus and tubes.

The controversy which surrounds Depo-Provera is not about its effectiveness. It is about its safety, how it is used and who it is used on. Below are listed some of the arguments used by health workers, family planning organisations and the manufacturer in order to get official approval for the general distribution of Depo-Provera as a contraceptive:

- Highly effective as a contraceptive, equal to or better than the combined oral contraceptive pill;
- Convenient and simple to administer. (This is true if the doctor's convenience is the main criterion.);
- Long action after a single injection. (This would be an advantage if there were no side effects or safety questions.);
- Doesn't have the problem of 'forgetting' which occurs with the pill;
- Doesn't have to be used at the time of intercourse as different from barrier methods like condoms or diaphragms;
- Doesn't effect lactation or breast feeding. (The pill decreases the amount of breast milk. However this advantage is a dubious one as the drug is excreted in breast milk. It is claimed that there are no significant effects on breast-feeding infants);
- No oestrogen side effects or complications. Oestrogen is present in the pill, and it is argued that Depo-Provera has a particular advantage for women who can't take the pill either because of oestrogen side effects or because of medical problems which mean that oestrogen shouldn't be given;

- Lack of periods may be a health benefit. After twelve months of using Depo-Provera more than half of the users don't get periods for months at a time;
- It is argued by Depo-Provera's supporters that these women are less likely to become anaemic. (Surely there are other ways to prevent anaemia);
- It decreases the incidence of vaginal thrush;
- Because it is injected and its effects last three months, Depo-Provera is suitable for women who are unable to accept responsibility for close adherence to dosage schedules required by oral contraceptive methods;

If some doctors experienced the so-called 'side effects' of some of the treatments they prescribe they may think twice before recommending a particular treatment. Conference participants asked the following questions of Dr. Peter Paterson, from Monash Medical Centre, who spoke on laser surgery (responses are abbreviated):

Q. How is the laser high energy beam technique performed?

A. Through the vagina.

Q. Any after effects?

A. Discomfort and discharge for a short time.

Q. How long has the technique been used?

A. Eight years.

Q. Is it still experimental?

A. No, not now.

Q. What sort of women is it used on?

A. Women with a good uterus but heavy periods.

Q. Are women having treatment only for heavy periods?

A. This is the basic reason.

Q. Do heavy periods endanger a woman's life?

A. They can be life threatening, and the woman may require a blood transfusion.

Q. Long-term effect/menopause?

A. Ovaries not altered. No effect on menopause.

Q. Where is it performed?

A. Monash is the only government hospital to cater for demand.

Q. Other side effects on menstruation?

A. Pain of menstruation is reduced fluid retention/sore breasts - similar.

Q. Is the procedure used for teenagers?

A. No, no one under 30 years old.

Q. Is it the same technique as used for cervical cancer?

A. Laser is used for cervical cancer.

Q. Young 32 year old woman, a very heavy bleeder, would this be suitable?

A. Yes, very suitable.

Q. Does the medical profession have a policy on disabled people? Or, just sterilise them all?

A. Monash has contact with disabled children and doesn't hold this position.

Q. Are there any guidelines for 'consent'?

A. I have been concerned to ascertain that the patient does understand the full implications. No, no guidelines as such.

Q. What's the fertility rate like?

A. No one has been able to have children after the procedure.

Q. Can lining be put back after laser surgery?

A. May be possible.

Q. What are the disadvantages of laser surgery?

A. Doesn't stop periods completely; - takes high doses of hormones to reduce lining.

Q. How much is known about the long term effects of laser surgery?

A. Not much is known!

What Was Said During the Medical Techniques Session

"We need more information about our health"

"Women's groups have evidence that the use of injectable contraceptives have increased dramatically"

"We shouldn't be satisfied until we get the information we need!"

"A bleed is different for each woman"

"Each of us 'bleed' we can talk to each other about it"

"How permanent is sterilisation?"

Doctors' reports tend to: centre on negatives of disabilities, not look at alternatives; not challenge capabilities of 'normal' mothers; rarely' discuss informed consent; complain that they cannot get information from patients; object to criticism.

A Legal Look at Medical Aspects

What Options Exist for Victoria, or Australia Generally?

"There are easier ways around these situations that would be much better and more effective like contraception. These options are much better but would need explaining for people who are not quite sure about how to go about these kinds of things. If you're not quite sure make an appointment with the Family Planning and discuss it with a person who will be able to help you work out which medication would be right for you. That is the best way to do it and I would think other people would agree or get mum to explain it to you. That's what my mother did, doesn't hurt to get some advice from your mum or someone in the family."

(Josie Atkinson, July 1990, Opening Speech to My Body, My Mind, My Choice).

The Legal Workshop at the conference was presented by Jeff Goldhar who is the Legal Officer of the Guardianship and Administration Board. He presented a paper in which his views, rather than those of the Board were represented. In this section we have used extracts from his paper, along with comments and discussion with participants.

Informed Consent

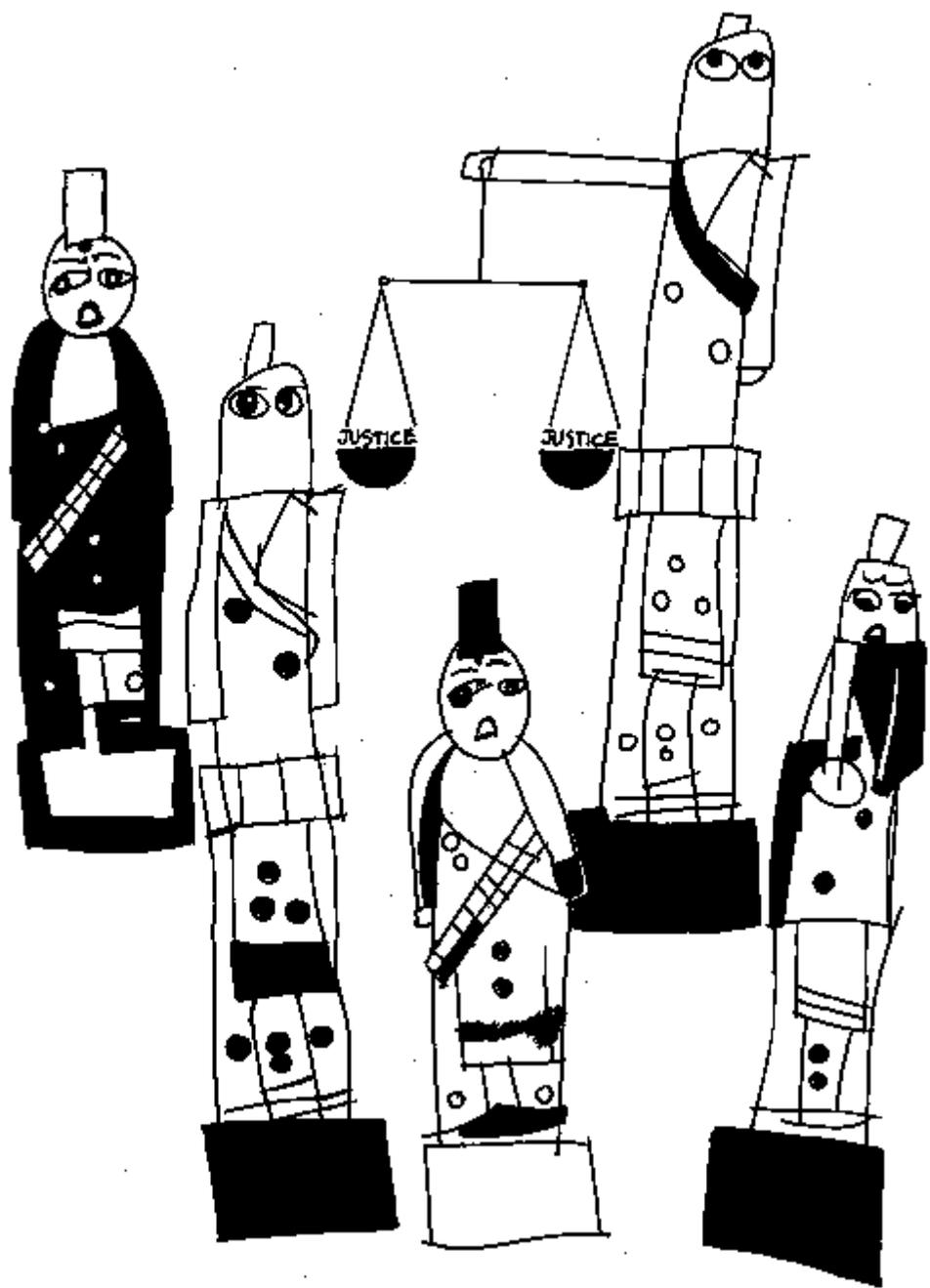
Before considering the main issues, I'll briefly look at informed consent and what it means. No-one can touch your body unless you agree to them doing so. That touching includes actions from kissing to major operations. They are all assaults. You can agree to an "assault" like a hug. You give your consent. If you refuse to consent or are not even asked, then the person doing the assaulting is committing a criminal act. He or she can be sued for damages. Doctors performing medical procedures, which include performing operations and giving injections, without consent, can lose their licence to practice medicine.

The consent for a medical procedure must be informed. That means the doctor must explain in detail its advantages, its risks and dangers, its possible side effects, the chances of success and the consequences of performing and not performing the procedure. The consent must be voluntary. That means there should not be any coercion or force. The doctor should give information about alternatives to the recommended procedure.

What does that mean in relation to sterilisation?

The doctor has to explain the full implications of the operation: it is irreversible, there may be psychological consequences, there may be circumstances in the future when the woman wants children. It has a failure rate. Post operation tests may be required to confirm success. This explaining needs to be in accessible language such as "you won't have babies now". The word 'irreversible' may have no meaning. "After the operation you may feel like....."

The notion of informed consent is a recent one. It has replaced the "doctor knows best" idea, when doctors considered that they knew what was good for their patient and carried on accordingly. There was no need to tell their patients anything. Nowadays doctors should not operate without first obtaining informed consent from their patients.



"Legal issues - pillars of community tend to obscure justice."

The next question is: who gives this consent?

The patient - the woman on whom the operation is going to be performed - is the obvious answer. Where the patient can understand the information necessary to give the consent, the competence of them.

So is another person giving consent such a bad thing? If you are in a coma, why shouldn't your family be asked to consent to any medical procedure? With a child too young to understand, parents should be asked whether they agree or disagree to any proposed procedure. These situations may be clear cut. Where it becomes hazy is when children become older and acquire some understanding of what is proposed. Then the issue of consent by another - third party consent - becomes more complex.

And even more so when someone consents for a person with an intellectual disability. The devaluation by society of people with an intellectual disability allows institutions, families and doctors to exempt them from the consent requirements for medical procedures. Sterilisation is one area where this occurs.

There are many reasons for this. Denial of sexual development is one. There are cultural reasons. Parents may fear having to bring up grandchildren. There are problems with third party consent in institutions. The state, with its coercive authority is present, as is administrative convenience.

The extent of sterilisations performed with third party consent in Australia has not been easy to figure out. Recent government reports in New South Wales, South Australia and Victoria have all come up with the same conclusion: doctors are performing unnecessary sterilisations on people with intellectual disabilities, whether they are living at home or in institutions. They are usually performed in hospitals. They don't keep statistics. The situation, however, is changing. More doctors have recognised that if a woman, who because of her disability, does not have the competence to give or refuse informed consent, the sterilisation operation should not proceed on the say-so of relatives or care givers. Where the woman is under 18, I believe that a judge of the Family Court has to consent. For an adult woman living in Victoria, the giving of consent is a matter for determination by the Guardianship and Administration Board.

In 1990 STAR wrote to the Director General of Community Services Victoria and asked for the figures on numbers of girls and women who between 1969 and 1989 in CSV institutions were on menstrual suppressants, had had tubal ligations or hysterectomies. The response indicated that Community Services Victoria didn't compile such information; it would cost too much to collate as it was on individual files.

The Court's Evidence

Some American courts have adopted a set of tests to help them decide whether sterilisation is in the woman's best interests. The Chief Justice of the Family Court (Australia) adopted them in 1988. They include:

1. The possibility that the woman could become pregnant.
2. The possibility that she would experience trauma or psychological damage if she became pregnant (and conversely trauma or psychological damage from the sterilisation operation).
3. The likelihood that she will voluntarily engage in sexual activity or be exposed to imposed sexual intercourse.
4. Her inability to understand reproduction or contraception and the likely permanence of that inability.
5. The feasibility and medical advisability of less drastic means of contraception (such as the Pill or hormonal treatment) both now and in the future.
6. The advisability of sterilisation now rather than in the future.
7. Her ability to care for a child and the possibility that she may, with a partner, care for a child.
8. Evidence that scientific or medical advances in the foreseeable future may improve the woman's condition, or that alternative and less drastic sterilisation procedures may be developed.

Sometimes what is needed to give an alternative a chance to succeed is time. For instance if a woman hasn't managed her menstruation as a teenager, then she can't simply be judged as unable to learn as an adult. All she may need is a real opportunity to learn about her body. Programs are often rejected before they are allowed to be started.

Some specialists complain about their inability to obtain intelligible responses from their patients at an initial consultation. It's important to remember.....that the doctor may come in after a long queue of medical and non-medical professionals have seen that woman.

As one Canadian commentator pointed out: "physicians (doctors) must learn to communicate with their patients."

The getting of informed consent seems to have a low priority. Doctors don't usually refer to the possibility of their patients giving informed consent to any proposed treatment. There are, of course, many situations where consent cannot be obtained, but the attempt should be made.

In contrast to doctors, non-medical professionals may paint a different picture in their reports. One nurse started her report by looking at her client's communication abilities and commented positively on her school progress. One section was headed 'abilities', another suggested a meeting to find out the client's wishes.

Similarly other non-medical reports highlight abilities and downplay social problems. This is especially so with menstrual management. House staff contend that they can cope with their resident's period problems. Confidence exuded by these paid care-givers is often at odds with parents' pessimistic opinions of their daughters' abilities. Whether the paid workers are realistic or not is sometimes arguable.

Doctors don't tackle the possibility that their patient could give informed consent with education and training. Reports by teachers of human relationship courses, however, do. They often have a wide- ranging look at learning abilities and difficulties. They usually conclude with down-to-earth assessment of future prospects. Unlike lawyers, judicial decision-makers and specialists, these are the people who will impart skills long after any court hearing.

The professional should find out clearly who has the problem and what the problem really is. The professional can then say what solution is proposed. That can be tested against a solution that would be suggested for an intellectually competent woman. If the proposed recommendation is different, why? Is the solution commensurate with the problem?

Professionals often give a prognosis of the effectiveness of any solution they propose. If the professional is recommending sterilisation, surely she or he could try to predict what the impact would be on the woman if the sterilisation went ahead and what would happen if it did not proceed. Of course the professional should report on the competency of the woman to give informed consent. They should remember the advice of a Canadian doctor: *"Professional people assume people with a mental handicap are incapable of informed consent.....they are perfectly capable of understanding a great deal of what is said to them provided the explanation is given properly and clearly."*

Here is an ideal set of steps to assist in working through sterilisation for girls and women with intellectual disability:

- Who has the problem?
- What is the problem?
- What would be recommended for an intellectual competent person?
- If it is different, why?
- Is the proposed solution proportionate to the problem?
- What happens if the sterilisation goes ahead?
- What if it does not?

Making sure guardians and Courts are making informed decisions when a woman with an intellectual disability can't was a major concern. The question of informed consent remains central and important.

Excerpts from the discussion between conference participants and Jeff Goldhar:

Q. What form does the doctor/patient relationship take?.

A. No-one can touch your body without your agreement. If a doctor does something without consent, he/she can lose their licence. Doctors must explain in quite some detail the procedure and all the outcomes of the action. After this is 'informed consent' the person is now 'knowing and agreeing.'

Q. How do you determine that a person is informed?

A. It is very difficult to determine that a person may really understand the finality of a sterilisation.

Q. Who makes the decision on whether you can keep the baby?

A. Competence should be presumed. Where the right to make a decision is taken away, it should only occur after rigorous challenge.

Q. My parents don't think I'm capable of having a family. What do you think?

A. It's very difficult to know.

Consent

The following is taken from a survey of parents regarding sterilisation of girls with intellectual disabilities. This was included in our legal issues kit.

Parents - Cincinnati Adolescent Clinic 1983:

69 parents were interviewed regarding the sterilisation of their intellectually disabled daughters. 32 parents had thought of sterilisation; the more disabled the daughter the more likely they were to have considered it. Briefly, parents of mildly disabled women were 3 times as likely to have considered tubal ligation rather than hysterectomy.

Parents of girls with severe disabilities were 3 times as likely to have considered hysterectomy.

Parents of those with moderate disabilities were almost equally divided between the procedures.

13 of the 32 parents who had considered sterilisation decided against it. Their reasons are interesting:

6 said: *"My daughter's problems can be handled with birth control."*

2 said: *"My daughter's difficulty with menstruation does not justify sterilisation."*

2 said: *Their daughters had proper supervision and did not need sterilisation protection.*

1 said: *"Daughter could be responsible for her own sexual activity."*

1 said: *"Surgery of a healthy body is mutilation."*

1 said: *"...felt her daughter's venereal disease would result in a defective child but later learned that her fear was unfounded."*

18 parents were still seeking sterilisations. 17 were parents of women with severe intellectual disabilities and were pursuing hysterectomy.

The common primary reason was for protection from pregnancy but 6 of the hysterectomy seekers gave 'elimination of menses and related problems' as their primary reason for wanting the sterilisation.

("Issues in Fertility Control for Mentally Retarded Female Adolescents: Parental Attitudes Toward Sterilisation" Alice Passer et al, Paediatrics, Vol 73, No.4, April 1984.)

Recommendations

Women's Issues and Rights

The following recommendations made at the conference relate to issues which participants believed should be placed on agendas as women's issues. That is, to be supported as such by women to ensure action is undertaken in these areas. Women with intellectual disabilities seek control of their lives and want respect for the rights of women unable to fully participate in the decisions which affect their lives.

Recommendations

Sterilisation issues to be worked on as women's issues.

Good decisions must be made for women who can't make them.

As role models for women play a powerful part in shaping perceptions and attitudes, more resources should be directed to address this area. Role models have a great impact on education, life experiences and skills which add to personal empowerment.

Stop the use of menstrual suppressants without consent.

Every woman should be taught her rights as a sexual person from an early age.

Women have the right not to be touched against their will.

It is not just women with disabilities who need to be informed. Doctors, nurses and lawyers often show great ignorance regarding the rights and dignity of women with intellectual disabilities.

Links need to be further developed between medical professionals, hospitals, women's health services and individuals.

Everyone should have the right to make good decisions about their lives and bodies.

We have the right to say what happens to us.

We have the right to privacy and personal space.

We want to learn to protect ourselves.

We want relationships too.

We want privacy.

Intellectual Disability Services must develop and implement policies on human relations with us.

Human relations must be identified in all General Service Plans as a separate category.

Legal

The two major legal issues that participants wanted to discuss and develop recommendations on were informed decision making and consent, and who should be making decisions when girls and women with intellectual disabilities can't. Participants were concerned with the long time applications for hysterectomy took to get through the Family Court, and the way in which the process alienated many people. Many people felt that the Family Court and lawyers needed a great deal of educating and information before their decisions could assure the least restrictive alternative for women. This was highlighted by judges in various states having totally different views on the issue and the rights of girls and women with intellectual disabilities. Women

with intellectual disabilities who attended the conference sought information, the right to be heard and the right to be decision makers. Participants agreed that a legal body rather than parents was needed to facilitate decision making for girls unable to make decisions themselves about irreversible and non-therapeutic forms of menstrual management and contraception.

Recommendations

Office of the Public Advocate and Guardianship Board to challenge the opinions of doctors relating to informed consent. To apply pressure to have things change.

Guardianship and Administration Board to be involved in decisions for hysterectomy for women under 18 years.

Health

Prior to the conference STAR contacted the Health Department and invited them to participate in the conference. The response implied that sterilisation of girls and women with an intellectual disability was a community service issue, not a health issue. This was rejected by conference participants who identified the medical profession as being in a primary position of power in suggesting, endorsing and performing hysterectomies and tubal ligations without working through their appropriateness and too often without the consent of the women. STAR has identified the medical profession as needing education on these issues. The medical profession needs to take personal responsibility in ensuring that the best interests of the 'patient' not society, not parents, not services, is respected.

Recommendations

Doctors to learn to communicate with patients.

Improved training in the area of disability is required for medical professionals.

Doctors to ask - if this woman did not have a disability, how would I treat her?

Doctors to ask - what will happen in the future if a woman is sterilised?

When giving out information doctors must check that the information is clearly understood.

Doctors should ensure that women with intellectual disabilities are provided with quality health care. Steps should include: i) referral elsewhere; ii) obtaining adequate information; iii) access to available alternatives.

Other methods should also be explored: such as naturopathy, Chinese medicine, herbal treatments, exercises or a combination of treatments.

Information

Information was a theme present in all areas discussed. We identified that information is needed in many areas and that this information must be accessible and readily available.

Recommendations

These issues, which we have talked about for two days, are about power, there must be strategies for EMPOWERMENT: (a) assertiveness; (b) accessible information and (c) information from a variety of sources. People may have information, but must have the power to act on it. The process to get this power may include, assertiveness, communication and information.

Information wanted

We want to know how many women have had tubal ligations and hysterectomies without informed consent.

Information discussing the advantages and disadvantages of medications, operations, and other health related issues is needed.

We want to know what the side effects of depo-provera are.

Care givers need more information on menstrual options.

Jeff Goldhar' s paper should be presented to other professionals including doctors.

STAR to organise a register of ideologically sound doctors.

Access and quality

We keep learning all the time so we need information all the time.

We want unbiased information.

We have the right to learn.

Accurate and accessible information is needed for women to make informed decisions.

We want to be able to question information because lots of varied information exists.

There is not enough clear evidence on Depo-provera to make informed decisions possible.

Information services

Information should come from lots of sources: family, friends, education, health centres, family planning centres, government bodies, support workers, institutions and doctors.

Information providers are to be responsible for ensuring that information is meaningful, accurate and accessible.

Services and support need to be available in the country, people in country areas are desperate for information and services.

Education

Recommendations

Community Education

Better understanding and communication on disability issues and the rights of women with intellectual disability be fostered within the general community.

That education on sterilisation issues be provided to people in institutions and isolated rural communities.

That the community be educated about the sexuality of women with intellectual disabilities.

Human relations to be included as a part of educational programs and curriculums.

Menstruating is considered a taboo. Issues surrounding women's health need to be more open and, more easily and readily discussed.

Fertility, menstruation and childbirth should be seen as natural and positive for women with intellectual disabilities.

Training

We need to educate doctors and parents on personal and sexual rights of women with intellectual disabilities.

Following appropriate training, community residential staff should be involved in educating people close to them instead of totally relying on experts. This is so things don't become too specialist.

Resources

Rights need resourcing. Self determination requires resourcing. Learning to manage ones own body, needs resourcing. Community living needs resourcing. We know that many women with intellectual disabilities are able to manage their own menstruation but are unable to do so because insufficient priority is given to the resources required. Participants had a clear understanding of the areas that require resourcing.

Recommendations

For education in human relations

We want more resources to be given to the human relations area in Victoria.

Increase the numbers of educators and counsellors.

Adequate resources for these workers.

For training in mainstream education

Money is needed to generate more information and workers in this area. Education services need to be better resourced and more training to be given in mainstream education.

Support for care givers

Resources and supports are required for care givers and support workers, to assist people to deal with such personal situations.

Information and practical assistance on physical issues

We need services to assist and accessible information on menstrual management.

State and Federal Governments to be lobbied to make family services and health services readily available.

Training for intellectual disability staff

Staff to have human relations education before they start.

For country areas

People in country areas require more accessible resources, as theirs are even more stressed than for people in metropolitan areas.