MARRIAGE, PARENTING, BIRTH CONTROL AND STERILIZATION FOR CITIZENS WHO ARE MENTALLY RETARDED

by Melvin D. Heckt, October, 1979

I am pleased to share with you my observations and opinions relating to these "HOT" and "Controversial Issues" which are about as hot and controversial as the issue of the right of a woman who is retarded to have an abortion.

In preparation for today, I have read the written materials of a number of "experts" (a list is attached), a number of court decisions and law review articles, and have interviewed 10 experts from the Twin Cities who work with mothers who are retarded and their children. Most of these experts work with the retarded persons on a daily basis and are, or have been, members of highly skilled multi-disciplinary teams. They include a physician, a clinical supervisor of a Public Health Department, a director of a program for 40 retarded mothers and their children, a Ramsey and a Hennepin County social worker, a SPARC and a MARC counselor, a special education department director of an early education and stimulation program for retarded mothers and their children and a State Department of Public Welfare employee who decides which mentally retarded persons under State Guardianship may be considered for court review of their petitions for sterilization.

If one reads the written materials of experts in the fields of religion, ethics, morality, law, psychiatry, psychology, social work, MR advocacy or other MR professions, one discovers that the experts frequently disagree on what is mental retardation, who is

and who is not retarded, and too many fail to differentiate among the abilities or lack of abilities of people who may be included in the sub-grouping of the mildly retarded, let alone differentiating among people who are moderately, severely or profoundly retarded or who have multiple physical and mental handicaps in addition to being retarded. Too often the experts and we parents and ARC experts promote the same confusion by our printed and spoken words in lumping together all persons who are retarded as "the mentally retarded".

For example, my friend George Tarjan points out that the mildly retarded are not homogenous but may be included within at least two sub-groups. He suggests that the statistically larger group of mildly retarded, sometimes called the socio-cultural retarded, in most instances disappear into society when they become adults; they marry, have children, work competitively, manage their own finances and affairs and are no longer heard from in a mental retardation context. I would not define or label these people mentally retarded.

I am not going to discuss today the socio-cultural retarded, the slow learner, the learning disabled who is not retarded, the person who was erroneously put in a special education class because he was black, couldn't speak English, couldn't understand the middle-class white man's I.Q. test, was economically poor or different, or the person who was institutionalized or otherwise mislabeled or mis-diagnosed as retarded when in fact he was not.

Marriage and Parenting

The experts seem to be divided into three general groupings with some variation in each. I will call them Ivory Tower A, Ivory Tower B and Real World.

Ivory Tower A experts contend that no person who is retarded should marry or have children. In fact some Ivory Tower A experts contend that it is inevitable that governments in the future will grant or refuse licenses to a man and woman to have a baby. A recent UPI news story reported that although Educational Psychologist Jerry Bergman, of Bowling Green State University, was not pushing the idea, he suggested government should look at the idea of licensing couples to have babies. One proposal considered by certain scientists was that a couple would need an I.Q. above 80, earn more than $8000 per year, have no serious emotional problems and know how to care for children before receiving a license from the government to have a baby. If you failed one of the requirements, you and your mate would not be allowed to become parents. Their rationale was "Licensing of parents is less bad than having a lot of people dying—that if you can prevent reproduction you can prevent the least qualified from having children; that there is nothing a state can do now to stop persons who are mentally retarded from having as many children as they want."

Ivory Tower B experts contend that all persons who are mentally retarded should have the right to marry and/or have children.

These experts further contend that all statutes or common law decisions which prohibit or restrict marriage should now be repealed or overruled and that such rights to marry and have children are constitutional or natural law rights which comply with the espoused principles of normalization, least restrictive alternative and give the mentally retarded persons first rather than second class citizenship.

Real World Experts contend:

(1) Persons who are in fact profoundly or severely mentally retarded and some moderately retarded should not have the right to marry nor the right to have children and statutory and common law

prohibiting or restricting marriage should not be repealed or overruled with respect to these persons.

(2) Persons who are in fact mildly retarded (not including the socio-cultural retarded, the majority of whom presumably have no, or little, difficulty marrying and having children), and some moderately retarded persons should have a qualified or conditional right to marry but they either should not be encouraged or permitted to have children except under certain very restricted circumstances.

Rationale For Real World Position #1

To Real World experts including parents and professionals working daily with adults who are retarded, it appears devoid of all reason to suggest that profoundly and severely and some moderately retarded persons should have the right to marry even though they do not have the competency to understand the meaning of marriage, its contract, its responsibilities or be able to perform any or most aspects of the marital relationship. If given the right to marry, they would be subject to physical and mental abuse and financial and other exploitation. They are in need of protection by society and would receive none. If statutes and common law decisions prohibiting marriage were repealed and overruled, not even their parents, relatives, guardians or advocates could legally prevent such a marriage from occurring.

There is a legal Catch 22 in that we don't want the law changed in prohibiting marriage among profoundly or severely retarded persons and yet Ivory Tower and Real World experts are in general agreement that the law should be changed so as not to prohibit marriages among mildly retarded persons. Jeffrey Shuman wrote in the spring of 1978 that there were 37 states and the District of Columbia which have statutes severely restricting or prohibiting the rights of mentally retarded persons to marry. I have not researched these

statutes. I suspect, although I have no proof and could very well be wrong, that these laws prohibiting marriage deter very few mildly retarded persons from marriage in comparison with other deterents.

Rationale For Real World Position #2

The rationale of those experts who advocate a qualified or conditional right to the marriage but no children for mildly and some moderately retarded persons is as follows:

a. Marriage: Yes.

1. Marriage among two mildly retarded persons can provide companionship rather than loneliness, love rather than hate, healthy rather than unhealthy sexual activity, a feeling of security, acceptance and first class citizenship rather than a feeling of being a social outcast One woman physician interviewed said, "Marriage, yes, children, no." I have seen it help in employment; I am convinced it can assist in minimizing the risk of drug addiction, alcoholism, sexual exploitation or being sexually exploited; it certainly can minimize the person's development of negative attitudes toward sexual activity.

2. Most of the experts I talked with felt it would be equally as important if not more important for a retarded person to be required to receive an unbiased education and counseling about marriage, its duties and responsibilities, sex, birth control, and possible sterilization, and discussion with the parents or relatives before marriage, as it would be for him or her to be required to take a blood test as a condition to receiving a license to marry. All suggested the importance of full participation of the mildly retarded persons and their relatives as well as good counseling and education. Parental or relative support of the mildly retarded couple is important and can help.

b. Children - No, with few exceptions.

Again, I am not including socio-cultural retarded persons or those who have been mislabeled or misdiagnosed as retarded. I have personal knowledge of only 6 married couples in which both spouses were mentally retarded, who did not have children and one or both were sterilized. Over the past 10 years I have frequently asked social workers and others this question: "Do you know a married or unmarried couple where both spouses are retarded and who have children and live together as a family unit where the marriage and the parenting could be considered under any stretch of the imagination successful, and I have received these answers: I have heard of but don't know them, or the man or woman is normal but the other spouse is retarded, or they fall into the socio-cultural category. I have likewise not been impressed with the research findings I have read. I may not have read the right research studies. But I recall the study of 80 persons who had been institutionalized in California where the researchers reported that the FSIfor males at time of discharge was 78.1 and females 71.3, with a range of 53-110. The study also indicated that there was a paucity of information about the 32 children and concluded that "with new and enlightened community preparation methods, there is no apparent reason to prevent any once institutionalized retardates fromtaking on the responsibilities of marriage and parenthood. However, it must be emphasized that the marriages investigated here have been of relatively short duration. Further research is needed to assess the long-term status and desirability of the partnership as well as the development and potential of their offspring."

I would now like to share with you what I discovered in my interviews with 10 highly trained and professionally competent and experienced experts from the Twin Cities:

1). There was almost complete agreement that marriages among two mildly retarded people who received good counseling and education before marriage, who received the support of their families and the community and who did not have children were usually successful but when children were involved the marriages were almost always unsuccessful and ended in separation or divorce.

2). Many mildly retarded women cohabit with non-retarded "sick men" who are alcoholics, drug addicts, mentally ill or older emotionally sick men who are social misfits. These women frequently get pregnant by these men and only occasionally marry them.

3). Many mildly retarded women are victims of incest and hate or have unhealthy attitudes toward sex and have unwanted children.

4). Many mildly retarded women, like many other women who are victims of abject poverty have one or more unwanted babies in order to qualify for AFDC payments which are larger than SSI or Social Security or general public assistance grants. As one professional said, mildly retarded mothers may be retarded, but they know about governmental financial assistance.

5). Many mildly retarded women become extremely depressed with their having had a baby. Some have a baby whom they feel will give them status, I'm OK, you're OK, and someone who will always love them, and then once again see themselves as a failure.

6). Many "mildly retarded" women who are successful in raising their children turn out not to be retarded upon re-testing.

7). Most mildly retarded mothers at some point in time either voluntarily give up their children for foster care or have their children taken from them by the welfare system and courts. As

one local expert said, "I started out with a bias that all mildly retarded should have the right to marry and procreate, and that if we only provide the right education and support program this could be successful. I must now admit, that with all of our homemaking, nutritional, social work, mother-counseling education and group counseling and early infant stimulation programs, our system of education does not enable the mildly retarded to cope with the emotional needs and developmental changes in the child. We can teach themhow to take care of the children's physical needs, but honestly, we have not been successful. I have yet to see a mildly retarded mother retain her child into the teens.

8). Many mildly retarded mothers severely physically abuse or neglect their babies. Some may take their babies to the bowling alley every night between the hours of 10 P.M. and 12 P. M. I have Seen mothers severely kick their children in our center where they come with their children four days a week, or if some attractive offer is received they will forget to feed cr properly clothe or leave their children unattended all evening. Or, I congratulated the mother upon having a beautiful baby and she stuck out her tongue and made the usual sound of disgust at the thought.

9). A number of mildly retarded mothers have had healthy normal babies born but have diluted their milk or otherwise caused their babies to become retarded by reason of malnutrition, starvation or other physical abuse. One expert told about a mildly retarded mother who lived with her child in a foster care home, who had homemaker services once a week, who came to the center four days a week and when the center investigated why the baby wasn't gaining weight, it discovered that the mother was diluting the milk and the healthy, normal baby became brain damaged by reason of strep throat.

10). Several experts suggested that it might be possible to place the mildly retarded mother and father and their child or children in a 24-hour foster care home and give them all of the expert help from public health nurses, homemaker, nutritionists, social workers, psychologists, doctors, child care workers and early infant stimulation education and find successful parenting. Others suggested that if this were done over a long period of time a number of the retarded mothers and fathers would resent this intrusion into their privacy much more than the loss of their right to procreate. Other experts indicated that when this was tried, some of the mildly retarded mothers became confused and their confusion turned into violence toward their child. Others resented the intrusion into their privacy; some of the confusion results from different professionals offering conflicting or different suggestions. Sometimes the confusion results from turn-over of staff, or the mother being shifted into 2, 3, or 4 different programs. Sometimes some retarded mothers realize long before the well intentioned expert that she can't cope with the child.

Many experts would have difficulty publicly expressing an opinion that a mildly retarded person should not have the right to procreate. On the other hand there was surprising agreement that if you omit the socio-cultural retarded person and the mislabeled or misdiagnosed person, the success ratio in parenting by mildly or moderately retarded person was extremely small even with the application of the most advanced educational and counseling techniques. Many also suggested that they also had a responsibility to the unborn fetus as well as to the children born of such marriages.

I am generally inclined to agree with Dr. Travis Thompson who stated, "* *certain behavioral deficiencies occur with sufficient frequency among retarded persons that social and legal mechanisms

designed to evaluate minimal competencies to enter into certain contracts and undertake parenthood can be justified as rational and not unduly intrusive, when conducted on a case-by-case basis. Finally, efforts to deny difference between retarded and non-retarded persons are misguided because they are based on the fallacious reasoning that since some features of retardation are shared by non-retarded people, it makes no sense to distinguish retarded from non-retarded people. Such an argument is as absurd as suggesting that since the concept of twilight is so vague, there is no difference between day and night. In short, mild retardation involves a measurable set of behavioral dispositions, which can be expressed in terms of measurable overt competencies."

This is really what many intelligent and caring parents of retarded children have been saying for quite some time.

Other Catch 22 Situations in Marriage

1). Social Security. As you know, if a retarded person is entitled to receive regular social security, this entitlement ceases upon marriage. Although I believe this legal barrier should be removed, until it is removed by Congress, I am anticipating reading about a law suit brought by or on behalf of a retarded person against a counselor or advocate for malpractice in recommending and advising and encouraging the retarded person to marry, thereby causing the retarded person in reliance thereon to marry and lose his $200 per month social security check for his 60years life expectancy. Thus it appears that from this perspective retarded people, like senior citizens in Florida, should not marry, but rather live together so that one does not lose her or his, or both, social security income.

2). SSI and Medicaid. Although some experts suggest that one should not lose one's SSI entitlement by marriage. I suspect that in the real world some do. Also with respect to Medicaid or medical assistance, some states have lower income and asset levels of entitlement when the income and assets are combined through

marriage than when the permissible income and asset levels are separated because the people are not married. Here again any such barriers to marriage should be removed.

3). Also some retarded persons may want to marry and engage in heterosexual activity but refuse to do either because of fear of pregnancy of the person herself, the legal and financial barriers to securing sterilization, or social or family pressures or influences against same.

Birth Control and Sterilization.

Many of you have heard experts say no minor child should be sterilized for any reason and especially a hysterectomy should not be authorized for hygenic-menstrual problems; behavior modification and good educational techniques will solve the problem. I would like to share with you a true story. Last June NARC referred to me a California mother of a 14-year old profoundly to severely retarded daughter who is hyperactive and hyper-irritable, who was diagnosed as having Cornelia De Lange Syndrome. She first had per period at age 10, and has had severe problems ever since; the school nurse stated she has a history of physical illness during and at time weeks before her menstruation; this is demonstrated by diarrhea, vomiting, pallor, dizziness and syncope. She has a history of eating and smearing her vaginal drainages. Her dress has to be pinned over her long pants to keep her hands out of her perineal area. She has been found eating her Kotex pad. Her hyperactivity increase with the sight of blood. A number of University medical doctors, the local doctor, the nurses, teachers and school psychologist all agreed that she could not raise children and that for hygienic and health reasons she should have a hysterectomy. The mother received a letter from a University doctor stating "It is strongly recommended that this young lady have an hysterectomy to prevent an unwanted pregnancy. At the present time such an operation would

be generally illegal in the State of California as one could not obtain an informed consent from this young lady. I believe that withholding such a surgical procedure from the young lady is medically and ethically unsound. The mother contacted numerous doctors, she received 11 letters of proof; she contacted the AMA, the Department of Health, legislators, congressmen, senators and the governor, the Protective and Advocacy Department and the National Association of Mental Retardation Program Director for help, and without success.

I put the mother in touch with a woman OB-GYN specialist in Minneapolis who performed a vaginal hysterectomy, leaving the ovaries, upon her daughter. This doctor wrote the mother and contacted a number of physicians in California and several Universities without success. I was just getting ready to call the doctor one day two weeks ago when I got a call from the mother. She was in Minneapolis; her daughter had a vaginal hysterectomy, leaving the ovaries, in one of our Minneapolis hospitals and was doing fine. The mother thanked me and told me how much she liked and respected the doctor and hospital staff.

In one sense I was happy I could help. In another, I was damn mad that this mother whose husband was partially disabled and worked in casual employment, had to pay out of her savings the doctor and hospital bill, 7 days of hotel bill, and air transportation from California to Minneapolis to secure needed services for her daughter because of court decisions, HEW regulations and the justifiable fear of doctors in California of malpractice litigation. I have the mother's permission to tell this story. It is true. No one will convince me that this 14-year old's civil liberties were violated; rather she received necessary surgery due to the persistence of a very caring mother who wouldn't give up.

It is rather clear to me that courts, lawyers, and experts in the fields of mental retardation are having a very difficult time agreeing upon or interpreting the words "Involuntary Sterilization", "Voluntary Sterilization", "consent" and "informed consent". Some court decisions and writers suggest that a person must be fully informed of all risks before consenting to surgery of any kind. I don't know anyone who is fully informed about anything. Likewise, recent AMA studies of patients' later recall about information received before surgery leaves much to be desired and is causing some doctors and hospitals and their attorneys to consider tape recording and overhaul of their consent forms. There is also the real danger that if you over inform a person about all possible risks of surgery that the person will either have a cardiac arrest on the operating table or will refuse necessary surgery.

Much has been written about the horrors of involuntary sterilization of the Jews by Hitler and by a number of black nonretarded women in Alabama who were forced to be sterilized against their will in order to get out of the rat hole institution they were in. These are horror stories which must be safeguarded against.

I would like to suggest that today and in the near future there are equally infamous horror stories of retarded people, who are competent to decide, who are being denied their right to be sterilized.

I want to share with you some of my concerns about well intentioned courts, civil libertarian lawyers and Mr. professionals.

First, I am concerned that courts in their desire to protect against the shocking forms of involuntary sterilization, performed upon institutionalized persons who are not in fact retarded, will

find it difficult making decisions which take into consideration the individual, the different levels of mental retardation and the different capabilities of retarded persons. This may be due in large part to the lack of or paucity of quality research findings upon which courts can make intelligent decisions.

Second, I am concerned that some lawyers become so impressed with the rights of the retarded that they ignore realistic solutions to problems, the limitation in capability and the lack of effective education and training of retarded persons to exercise certain rights without doing substantial harm and injury to themselves. For example, is it not pure folly to say that all moderately and mildly retarded persons attaining adult ages should have an unfettered right to drink booze at the local pub and not receive any education about the dangers and risks involved or how to drink in a socially acceptable manner; is it not folly to give an unfettered right to engage in sex but not a right to receive meaningful sex education so that he or she can avoid venereal disease or unwanted children.

Thirdly, I am also concerned about some civil libertarian lawyers and Mr. prof professionals desire to routinely involve the courts in all sterilizations of all retarded prsons, some of these lawyers and professionals argue that no parent or guardian with doctors approval should be able to make a decision to sterilize a retarded person if such person is incompetent to give his or her informed consent in the absence of a court order. They argue as follows:

a) The parents and guardians personal interests may conflict with those of the retarded person; parents and guardians should not be trusted with such decisions; parents and guardians substitute their judgment for that of a person who can't exercise judgment and who is unduly influenced by his parent and guardian and thus make a mockery out of voluntary sterilization; that parents and guardians

have faulty unfounded reasons such as the fear of retarded grandchildren, fear of responsibility for raising and paying for such grandchildren; unfounded fear that mildly and moderately retarded persons can't fulfill their responsibilities of parenthood, lack of knowledge that social agencies can aid the retarded parents in raising their children. These lawyers and professionals disagree with the current law in some states which "presumes that parents are more than adequately dedicated to their childrens' interests and may therefore without question exercise their power to arrange sterilization of their retarded children who cannot give informed consent and do not object to being sterilized.

I strongly disagree with these lawyers and professionals: I believe that parents do not make this decision without considerable thought and without checking with their doctor, other parents and other professionals; I believe parents like normal persons occasionally make a mistake, but I also believe that parents know their child and his capabilities better than most professionals, lawyers and courts and certainly are more concerned for the best interests of their child and will make fewer mistakes than would courts, professionals and lawyers in this decision making process.

b) Some also argue that before sterilization may be authorized, the court should not authorize any sterilization or birth control until the retarded person has had the opportunity to function as a parent and has failed to so function. This is hogwash.

c) They also argue that the court should insist that the parent or guardian prove that sterilization is in the best interests of the retarded person; that the court first decide whether the individual is or is not likely to be sexually active in the immediate future. (I can't imagine any judge wanting to decide what constitutes being sexually active or who may be so in the immediate future. Is

this issue not better left to the individual, his parent or guardian and his doctor than to a decision by experts or courts?)

d) Some also argue that a court should first determine that a retarded person is physically capable of procreation. To me this is a medical decision and in view of the fact that I was called Sterile Merrill, and Dort Infertile Myrtle, before we had our six children, I am not certain that a court should become or would want to become so involved. Naturally it would be ridiculous to sterilize someone who to a reasonable medical certainty was diagnosed as sterile.

e) Some argue that the court before authorizing sterilization should first determine that the retarded person has tried less drastic and restrictive forms of contraception and found them un-workable or unapplicable. I would hate to be the judge who told the retarded person he had to use a condom or she had to use the pill, the diaphram, the six-month shot or the rhythm method and later learned that the retarded woman had an unwanted pregnancy or death during childbirth, or killed her child or made her healthy, normal child retarded. Some retarded persons can't afford to buy the contraceptives; some can't use them without medically injurious consequences, and I for one do not recommend that a social worker be employed daily to come into their home and insure that she takes a pill or that he wears the condom.

I firmly believe that you and I as parents and our children who are retarded can benefit from reading and counseling on the subject but I believe that with very few exceptions, this decision should be made by the retarded person if he or she secures medical approval and if he or she desires it and can give consent and should be made by the parent or guardian if the doctor approves and the retarded person cannot give informed consent and does not object to it.

f) Some also argue that retarded persons have such a low self image because of parental, professional and public attitudes towards them that they do not realize their abilities to marry and raise children. This argument should not be treated lightly but given careful consideration by those of us who are parents, professionals and guardians. I am convinced that there are now many mildly and moderately retarded persons who with some assistance have the capability for, could benefit from and are being denied the opportunity for marriage. Although, Frank Menolascino assures me there are several studies showing that midly and moderately retarded parents have demonstrated success in raising children, my personal knowledge and experience has not born out this conclusion, except where one of the parents was of normal intelligence or where the people are within the socio-cultural group of mildly retarded. In any event, I do not believe that the court should be routinely involved with every retarded person who desires to be sterilized or whose parents desire same.

Naturally, if a retarded prson objects to being sterilized, I believe the court should determine whether or not the person should be sterilized and the individual's constitutional rights should be safeguarded.

Also I don't believe in parents or government or experts forcing or coercing retarded people to be or to not be sterilized against their will.

I would like to comment on the psychological impact of sterilization of retarded persons. I do agree with Phil Roos and other reputable experts who are concerned about this problem. I can agree that if a socio-cultural retarded person is sterilized against his/her will this can have very serious and traumatic adverse psychological effects upon the person. I also would agree that it would be equally unconscionable to trick or deceive a mildly or moderately

retarded person to unwittingly consent to a sterilization rather than the advised appendectomy for example.

In discussing this problem with some of the experts in my community, they have seen no adverse psychological effects of sterilization, except where there was fraud, deceit, forced sterilization or where total hysterectomies were performed on 12 and 13 and 14 year old children, and even in this situation they have noted no adverse effects when the ovaries were left intact.

I would suggest that from our experience the adverse psychological effect upon a retarded woman who did not want children but was denied effective birth control or sterilization and had an unwanted child, or severely physically abused her child, or caused her child to become retarded or who had her child removed from her in order to protect the child, may very well be considerably greater and cause more severe mental illness than the former. However, I believe we should encourage studies and research in this area as well.

In conclusion, it may very well be that in the future medical science may well eliminate the necessity for sterilization for anyone. But today, although it is labeled odious to some, it is a God sent blessing to others. For those who want to be sterilized, many of them are running into many legal barriers, court decisions, overly burdensome HEW regulations, lack of medical or financial assistance to secure them and thus are forced to have unwanted children. The other major barrier, which appears to contribute a real threat not only to the person who is retarded and wants to be sterilized, but also wants to have other surgery is the present day justifiable concern about the ability of a person to give legal informed consent. Unless the person can give such consent, the doctors and hospital is running a very great risk of later being

found guilty of medical malpractice. Another great danger is the denial of the retarded person's right to privacy. If he is forced to go to court when a normal person is not, if he is forced to pay for two or three doctors' opinion, and a normal person is not, if he must go before a hospital committee of several people and bare his entire sexual needs, desires and practices, and a normal person need not, are we not truly invading his right to privacy which he wants respected and insisting upon his right to procreate when he or she does not want children.

In conclusion, although we can all be most grateful for the contribution of lawyers, courts, government and M.R. professionals in helping to enrich the lives and dignity of citizens who are retarded, we parents and relatives must continue to be even more vigilant in order to insure that our courts, our lawyers, our government, our M.R. professionals and our ARC does not over protect, over interfere, over involve, over regulate, under fund and thereby become in the future the greatest risk and danger to our retarded citizens' rights to life, liberty and the pursuit of happiness.

Marriage and Sterilization

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