

August 21, 1976

THE MENTALLY RETARDED CITIZEN AND THE LAW

WASHINGTON ARC

by MELVIN D. HECKT

I AM THRILLED, EXCITED AND MOST HAPPY TO BE WITH EACH OF YOU AT THE 1976 ANNUAL CONVENTION OF THE WASHINGTON ASSOCIATION FOR RETARDED CITIZENS.

ALTHOUGH, I FEEL A BIT LIKE WINSTON CHURCHILL WHEN HE SAID, "I AM PREPARED TO MEET MY MAKER, BUT THE QUESTION IS WHETHER OR NOT MY MAKER IS PREPARED FOR THE ORDEAL OF MEETING ME", I DO FEEL MOST HONORED THAT YOU ASKED ME TO GIVE THIS KEYNOTE ADDRESS.

I AM A WHITE, ANGLO SAXON, PROTESTANT, UPPER MIDDLE CLASS, REPUBLICAN LAWYER. DURING THE PAST 24 YEARS, WHILE PARTICIPATING WITH MANY OTHERS IN THE FIGHT FOR MENTALLY RETARDED CITIZENS, I HAVE WEEKLY IF NOT DAILY FELT LIKE A POOR BLACK, BROWN OR WHITE, OR AN UNEMPLOYED RETARDED, MENTALLY ILL, OR PHYSICALLY DISABLED PERSON WHO WANTS TO WORK, OR AN EX-CON WHO WANTS TO GO STRAIGHT, OR AN ADDICT OR ALCOHOLIC WHO WANTS TO KICK THE HABIT. I, TOO, HAVE FELT LIKE A TUNED-OUT AMERICAN. I BELIEVE WE ALL SHARE THIS FEELING. I BELIEVE ONE CANNOT REALLY BE TUNED-IN UNLESS ONE IS ALSO TUNED-OUT.

OUR "ONE ARC" CONSISTING OF THE LOCAL, STATE AND NATIONAL ARC'S CAN BE JUSTLY PROUD OF THE PROGRESS MADE DURING THE PAST 25 YEARS IN DEVELOPING DIAGNOSTIC CENTERS, COUNSELLING SERVICES, DAY ACTIVITY CENTERS, EDUCATIONAL CLASSES, SHELTERED WORKSHOPS, RESIDENTIAL FACILITIES, WORK OPPORTUNITIES, RELIGIOUS AND RECREATIONAL PROGRAMS FOR SOME RETARDED PERSONS.

HOWEVER, WE ARE REALISTIC: WE KNOW THAT SUBSTANTIAL NUMBERS OF RETARDED CITIZENS ARE NOT RECEIVING THESE SERVICES AND ARE DOOMED TO WAREHOUSE, HOG BARN LIVING, TOTAL DEPENDENCE UPON THE STATE, AND A DEHUMANIZING LIFE WITH NONE OF THE CONSTITUTIONAL, CIVIL AND LEGAL

RIGHTS AND LIBERTIES WHICH YOU AND I TAKE FOR GRANTED, UNLESS OUR NATION TAKES ACTION AND MAKES CHANGE.

IF WE LISTEN TO THE PAST IN FACING THE FUTURE, WE KNOW THAT THE MEEK SHALL NOT INHERIT THE EARTH UNLESS YOU AND I AND THE MAJORITY OF OUR CITIZENS ARE ACTIVISTS: OTHERWISE, THE MOST THE MEEK SHALL INHERIT IS 6 FEET OF IT.

IF WE ARE TO MEET OUR RESPONSIBILITIES TO RETARDED CITIZENS, WE MUST AND WE SHALL STRENGTHEN OUR ONE ARC AT ALL LEVELS; WE MUST HAVE A MEMBERSHIP OF 1 MILLION; ALL RETARDED PERSONS, ALL PARENTS AND RELATIVES AND FRIENDS, WHETHER BLACK, BROWN, RED, YELLOW OR WHITE, WHETHER RICH OR POOR, WHETHER YOUNG OR OLD OF ALL RACES, RELIGIONS AND CREEDS AND NATIONALITIES MUST BECOME AND STAY MEMBERS OF OUR ONE ARC; IF EACH RETARDED CITIZEN IS TO HAVE A FRIEND AND ADVOCATE AND IF HIS SERVICES ARE TO BE PROVIDED AND MONITORED EFFECTIVELY, OUR LOCAL ARC'S MUST CHANGE: OUR METROPOLITAN ARC'S MUST PRESERVE THE STRENGTHS OF CENTRALIZATION BUT IF THEY ARE TO BE IN FACT GRASS ROOTS ADVOCACY ORGANIZATIONS, THEY MUST SUBDIVIDE INTO SUB-UNITS FOR EACH WARD AND EACH SUBURB; OUR RURAL ARC'S MUST DEVELOP MORE AND STRONGER ARC'S SO THAT EACH RETARDED CITIZEN IN THE MOST SPARSELY POPULATED AREA HAS AN EFFECTIVE ORGANIZATION CONCERNED AND EFFECTIVELY WORKING TO GUARANTEE HIS RIGHTS, LIBERTIES AND OPPORTUNITIES.

ANOTHER THING OUR ONE ARC MUST DO IS TO ENCOURAGE OUR MEMBERS TO ASSUME JOBS AND RESPONSIBILITIES AND LEADERSHIP. DON'T LET ANY ONE TELL YOU THAT WE DON'T NEED MORE VOLUNTEER EFFORT OR THAT WE NEED LESS PROFESSIONAL ASSISTANCE. TO BE STRONG WE NEED MORE PROFESSIONALS AND VOLUNTEERS WORKING TOGETHER AND NOT AGAINST EACH OTHER.

I WOULD NOW LIKE TO DISCUSS WITH YOU SOME OF THE PERSONS WHO ARE RETARDED WHOM YOU AND I HAVE KNOWN. I WOULD ALSO LIKE TO SUGGEST THAT ALTHOUGH SOME ARE NOW RECEIVING CERTAIN OPPORTUNITIES AND RIGHTS, THAT BY THE YEAR 2000, ALL RETARDED CITIZENS SHOULD HAVE THE OPPORTUNITY,

IF CAPABLE, TO POSSESS THE RIGHTS I AM ABOUT TO DESCRIBE.

ALEXANDER'S MOTHER WILL RECEIVE ADEQUATE FOOD, CLOTHING, HOUSING, MEDICAL, NURSING AND HOSPITAL CARE SO THAT HE EITHER WILL NOT BE BORN MENTALLY RETARDED OR HIS CHANCE OF BEING SO BORN WILL BE SUBSTANTIALLY REDUCED.

ANDREA WILL HAVE THE RIGHT TO EQUAL ACCESS TO QUALITY HEALTH AND SOCIAL SERVICES ADAPTED TO NEED; SHE WILL HAVE THE RIGHT TO BE FREE FROM THE ARBITRARY DENIAL OF LIFESAVING MEDICAL SERVICES. THIS RIGHT RULES OUT ANY PRACTICE WHICH WOULD ALLOW A RETARDED PERSON TO DIE BASED UPON A JUDGMENT THAT THE QUALITY OF LIFE OF A RETARDED PERSON IS LESS THAN THAT OF OTHER CITIZENS, OR ANY ROUTINE POLICIES OR GUIDELINES PRE-DETERMINING THE WITHDRAWAL OF LIFE SUPPORT FROM IMPAIRED NEWBORN BABIES BASED ON PREDICTED DEVELOPMENTAL POTENTIAL. SHE WOULD ALSO HAVE THE RIGHT TO BE PROTECTED FROM UNNECESSARY AND EXPERIMENTAL PROCEDURES UNLESS SHE OR HER LEGAL REPRESENTATIVE HAS GIVEN INFORMED CONSENT. SHE WOULD ALSO HAVE THE RIGHT TO AN EARLY DIAGNOSIS AND TREATMENT, AN EVALUATION AND RE-EVALUATIONS AND PROGRAM DEVELOPMENT FOR HER ON AN ANNUAL BASIS; AND SHE WOULD HAVE THE RIGHT TO TREATMENT TO PREVENT OR MINIMIZE HER DISABILITY.(EX. PHENYLKETONURIA)

JOE WILL LIVE WITH HIS PARENTS OR SUBSTITUTE PARENTS WHILE A CHILD; WHEN HE BECOMES AN ADULT HE WILL LIVE IN A VARIETY OF RESIDENTIAL FACILITIES SUITED TO HIS DESIRES AND NEEDS; HIS HOME MAY BE A NORMAL HOUSE, A DUPLEX, A CONDOMINIUM, A HIGH-RISE APARTMENT, A GROUP HOME, A NURSING HOME; BUT IT WILL BE APPROPRIATE: IF IT IS AN INSTITUTION, IT WILL NOT BE AN OVERCROWDED COWN BARN INSTITUTION DORMITORY IN WHICH HE MUST STAND NUDE FOR TWO HOURS IN A LONG LINE TO BE BATHED OR ROCK IN A CHAIR OR ON THE FLOOR MASTURBATING FOR HIS ONLY RECREATION, PLAY OR PROGRAM: IF JOE LIVES IN A COMMUNITY, HE WILL LIVE IN DECENT HOUSING INSTEAD OF LIVING IN A CHEAP HOTEL OR A DILAPIDATED SHACK WITH LEAD BASED PAINT DRIPPING FROM THE CEILING

OR WITH RATS RUNNING RAMPANT ON THE FLOOR AND COCKROACHES COVERING THE TABLES AND CLOSETS. JOE ALSO WON'T HAVE TO LIVE IN A NURSING HOME OR HOSPITAL UNLESS HE NEEDS EXTENSIVE NURSING AND MEDICAL CARE. HE WILL NOT BE DENIED SUITABLE HOUSING BECAUSE OF ZONING LAWS OR LACK OF FINANCIAL ASSISTANCE.

LITTLE JIM WILL HAVE HIS DIAPERS CHANGED WHEN THEY ARE SOILED OR WET AND A DOCTOR TO TREAT HIS FEVER OR SORES: NO LONGER WILL LACK OF STAFF OR FUNDING BE AN ACCEPTABLE EXCUSE FOR NOT PROVIDING HUMANE AND REASONABLE CARE, FOOD AND CLOTHING.

TONY'S PARENTS OR SUBSTITUTE PARENTS WILL LEARN HOW TO HELP; THEY WON'T APPLY EXCESSIVE PRESSURE BY SAYING, "TONY, IF YOU WILL ONLY STUDY HARD, YOU CAN GO TO HARVARD"; NOR WILL THEY OVER-PROTECT HIM BUT RATHER WILL LEARN HOW TO ENCOURAGE HIM TO DO HIS BEST TO BE HAPPY WITH EACH ACCOMPLISHMENT AND TO BE HIMSELF; I CAN'T STRESS TOO MUCH THE IMPORTANCE OF TONY'S RIGHT TO BE HIMSELF; I AM OF THE OPINION THAT SOME PARENTS AND PROFESSIONALS ARE TODAY EXPECTING TOO MUCH OF SOME RETARDED CITIZENS WHO LIVE IN OUR COMMUNITIES AND INSTITUTIONS.

MARY WILL LEARN TO GET OUT OF BED AND WILL NOT BE PERMITTED TO STAY IN BED AND HAVE HER LITTLE ARMS AND LEGS ATROPHY FROM DISUSE.

TOM WILL BE TOILET TRAINED; LACK OF STAFF AND FUNDS WILL NO LONGER BE ACCEPTABLE AS AN EXCUSE FOR HIS NOT BEING TAUGHT SO BASIC AND IMPORTANT A FUNCTION.

BARB WILL TIE HER SHOES AND DRESS HERSELF.

PAUL WILL RECEIVE PRE-SCHOOL, SCHOOL, COMPENSATORY EDUCATION, VOCATIONAL EDUCATION AND TRAINING AND EMPLOYMENT OPPORTUNITY; NO LONGER WILL A SCHOOL DISTRICT BE ABLE TO DENY PAUL AN EDUCATION BY COPPING OUT WITH "WE HAVE NO MONEY - NO CLASS ROOMS - NO TEACHERS OR - HE ISN'T CAPABLE."

BILL WILL HAVE FRIENDS HIS OWN AGE AND WILL BE HAPPY; HE WILL

HAVE SOMEONE WHO CARES AND BEFRIENDS HIM OTHER THAN JUST HIS OWN PARENTS.

SALLY WILL TELL TIME AND ENJOY HER OWN POSSESSIONS AND PRIVACY.

SUE WON'T HAVE TO MARCH TO DINNER OR CANTEEN ONCE A MONTH OR TO ARTS AND CRAFTS ONCE A WEEK.

TIM WILL MAKE MANY DECISIONS FOR HIMSELF RATHER THAN BEING TOLD EVERYTHING HE MUST OR MUST NOT DO.

JOHN WILL SEE HIS FAMILY AND FRIENDS REGULARLY, GO TO CAMP, AND SPEND MOST OF HIS TIME OUTSIDE OF HIS RESIDENCE IN WORK, SHELTERED WORK, DAY ACTIVITY OR EDUCATIONAL AND RECREATIONAL PROGRAMS.

CINDY WILL HAVE COLORFUL DRAPES AND WALLS AND CARPET IN HER RESIDENCE.

SAM WILL BE EMPLOYED BECAUSE THE PUBLIC CARES ENOUGH TO SEE THAT HE IS TRAINED AND TAUGHT TO DO WHAT HE KNOWS HE CAN DO.

PETE WILL WORK 40 OR 50 HOURS PER WEEK IN THE COMMUNITY OR IN THE INSTITUTION AND WILL BE PAID A FAIR WAGE FOR HIS SERVICES. THERE WILL BE NO MORE \$2.00 PER MONTH PEONAGE; MOST WILL EARN A MINIMUM WAGE; ON THE OTHER HAND WE MUST BE CAREFUL NOT TO RIGIDLY APPLY MINIMUM WAGE LAWS IN SUCH A WAY THAT OUR RETARDED CITIZENS ARE THEREBY DENIED THE RIGHT TO WORK. PETE ALSO WILL HAVE THE RIGHT TO THE DIGNITY OF PAYING IN WHOLE OR IN PART FOR HIS BOARD AND ROOM IF HE IS ABLE.

ELEANOR WILL WORK IN THE COMMUNITY OR INSTITUTION LAUNDRY AND RECEIVE PRAISE FOR A JOB WELL DONE.

JANICE WILL BE ABLE TO GO TO THE PUBLIC PARK OR SWIMMING POOL AND WON'T BE STARED AT OR LAUGHED AT; THE PUBLIC WILL UNDERSTAND AND OUR YOUTH WILL LEAD THE WAY.

HARRY WILL HAVE THE OPPORTUNITY TO GO TO CHURCH IN THE COMMUNITY WITH ALL OTHER PEOPLE AND LEARN ABOUT HIS GOD.

MICKY WILL VOTE; TRANSPORTATION WILL BE PROVIDED AND IF HE CAN'T READ HE WILL BE GIVEN ASSISTANCE IN THE POLLING BOOTH AS IS NOW GIVEN TO THE BLIND. NATURALLY SOME PROFOUNDLY AND SEVERELY RETARDED PERSONS WILL NOT BE CAPABLE OF VOTING.

LARRY WON'T BE PUT IN A SPECIAL CLASS BECAUSE HE SPEAKS A FOREIGN LANGUAGE OR GREW UP IN A GHETTO OR RESERVATION, THOUGH HE IS NOT RETARDED.

BOB WILL RECEIVE RECREATIONAL AND PROGRAM SERVICES AND WILL NOT BE PUT IN SECLUSION, RESTRAINTS OR UNDER HEAVY SEDATION JUST BECAUSE THERE IS NO FUNDING FOR COMPETENT STAFF TO PROVIDE SUCH SERVICES.

RICHARD WILL HAVE ADVOCACY, PROTECTIVE AND LEGAL SERVICES AVAILABLE TO HIM. HE WILL HAVE CONSUMER RIGHTS; IF HE IS CHARGED WITH A CRIME HE WILL BE JUDGED ON HIS ABILITY TO UNDERSTAND; IF HE IS GUILTY HE WILL BE GIVEN CORRECTIONAL TREATMENT IN A SPECIALIZED FACILITY AND SOCIAL, PSYCHOLOGICAL, EDUCATIONAL AND REHABILITATION SERVICES TO HELP HIM GET STRAIGHTENED OUT; HE WILL NEITHER BE SENT TO A STATE PRISON WHERE HIS RIGHTS CAN BECOME COMPLETELY VIOLATED, NOR WILL HE BE SENT TO A STATE INSTITUTION FOR THE RETARDED WHERE HE CAN VIOLATE THE RIGHTS OF THE RESIDENTS THEREIN, OR WHERE HE CAN BE CONFINED FOR LIFE FOR HAVING COMMITTED AN OFFENSE WHICH WOULD UNDER THE CRIMINAL SYSTEM CALL FOR PROBATION OR 1 OR 2 YEARS OF CONFINEMENT.

IF JAKE CAN'T WORK, HE WILL BE GIVEN ADEQUATE FINANCIAL ASSISTANCE, OR A MINIMUM GUARANTEED INCOME WHICH WILL PERMIT HIM TO LIVE WITH PROPER FOOD, CLOTHING, HOUSING, RECREATION AND DIGNITY.

VIVIAN WILL HAVE THE RIGHT TO BE HERSELF AND NOT BE FORCED BY PROFESSIONALS TO CONTINUE UNDER THE INDIVIDUALIZED DEVELOPMENTAL MODEL AT AGE 65 BY FORCING HER TO ENGAGE IN EDUCATIONAL AND DEVELOPMENTAL PROGRAMS WHICH SHE FINDS NOT TO HER LIKING. FOR SO MANY YEARS WE

PARENTS AND PROFESSIONALS UNDERSOLD THEIR CAPABILITIES; NOW, I BELIEVE THERE IS A REAL DANGER THAT WE MAY BE SO "PROGRAMATIZING" THEM THAT WE MAY BE MAKING NERVOUS, ANXIETY AND GUILT RIDDEN WRECKS OUT OF SOME BY ATTEMPTING TO DEVELOP THEM BEYOND THEIR CAPABILITIES AND LEVEL OF CHOICE. THUS VIVIAN WILL HAVE THE RIGHT OF PERSONAL PRIVACY, THE RIGHT TO BE LEFT ALONE, THE RIGHT TO REFUSE GRATUITOUS ADVICE, THE RIGHT TO NOT TELL EVERY INTIMATE DETAIL TO A SOCIAL WORKER AND THE RIGHT NOT TO ANSWER THE DOOR.

OLGA AND QLAF WILL RECEIVE MEANINGFUL EDUCATION ABOUT LOVE, MARRIAGE AND SEX. THIS EDUCATION WILL BE OFFERED AT APPROPRIATE AGES AND TIMES AND WILL BE CONTINUING. THEY WILL LEARN ABOUT THE VARIOUS FORMS OF SEXUAL EXPRESSION, SOCIALLY ACCEPTABLE TIMES AND PLACES, THEIR RIGHTS AND THEIR RESPONSIBILITIES. THEY WILL LEARN ABOUT BIRTH CONTROL, THE CONDOM, THE IUD, THE PILL, THE 6-MONTH SHOT, THE VASECTOMY, THE TUBAL LIGATION, THE VAGINAL AND ABDOMINAL HYSTERECTOMY; THEY WILL LEARN ABOUT VENEREAL DISEASE, AND WILL BE GIVEN INDIVIDUAL AND NOT MASS COUNSELLING ABOUT THE VARIOUS FORMS OF CONTRACEPTION AND STERILIZATION; THERE WILL BE NO LAWS MANDATING STERILIZATION AS A CONDITION TO MARRIAGE OR FOR REMAINING IN OR BEING RELEASED ..... FROM AN INSTITUTION OR COMMUNITY RESIDENTIAL FACILITY OR FOR RECEIVING FINANCIAL AND MEDICAL ASSISTANCE. ON THE OTHER HAND, THEY WILL RECEIVE EXPERT COUNSELLING CONCERNING THEIR ABILITY OR LACK OF ABILITY TO MARRY OR TO RAISE CHILDREN. IF OLGA AND QLAF CAN BENEFIT FROM AND DESIRE MARRIAGE THEY WILL HAVE THIS RIGHT BUT THEY WILL ALSO HAVE THE RIGHT TO BE STERILIZED AND NOT HAVE CHILDREN; THEY WILL HAVE THE RIGHT TO RECEIVE MEDICAL ASSISTANCE FUNDS FOR STERILIZATION PROCEDURES AND NOT BE DISCRIMINATED AGAINST BECAUSE THEY ARE POOR AND RETARDED. IF OLGA CAN'T AFFORD THE PILL OR CAN'T REMEMBER TO TAKE IT OR MEDICALLY SHOULD NOT TAKE IT, SHE WILL NOT BE FORCED TO HAVE A SOCIAL WORKER COME TO HER HOME DAILY TO ADMINISTER IT; ALSO, IF OLGA AND OLAF ARE ABLE AND DESIRE TO MARRY BUT NOT HAVE CHILDREN, ONE OR THE OTHER OR BOTH WILL BE ABLE TO CHOOSE STERILIZATION

WITHOUT BEING DISCRIMINATED AGAINST BY A LAW REQUIRING A COURT ORDER OF APPROVAL OR A COURT ORDER REQUIRING THEM TO TRY OTHER LESS RESTRICTIVE FORMS OF CONTRACEPTION, RESULTING IN THEIR MISUSE AND HAVING AN UNWANTED CHILD. IF OLGA BECOMES PREGANT SHE WILL HAVE THE RIGHT TO SECURE AN ABORTION AND WILL NOT BE DENIED SAME BECAUSE SHE IS RETARDED AND POOR AND IN NEED OF MEDICAL ASSISTANCE. THIS RIGHT WILL NOT BE RESERVED SOLELY FOR THE RICH OR MIDDLE INCOME "NORMAL" PERSON.

OLGA AND QLAF REPRESENT MY OPINION OF THEIR RIGHT TO LOVE, SEX, MARRIAGE, BIRTH CONTROL, STERILIZATION, ABORTION AND NOT TO HAVE CHILDREN; I RECOGNIZE THAT NOT ALL RETARDED PERSONS HAVE THE CAPABILITY OR DESIRE TO OR SHOULD ENGAGE IN SUCH ACTIVITY; THESE ISSUES ARE HIGHLY CONTROVERSIAL BUT MUST BE FACED.

I AM CONVINCED OF THE FOLLOWING:

- 1) NARC MUST REPRESENT THE INTERESTS OF RETARDED CITIZENS OF ALL AGES AND ALL LEVELS OF RETARDATION.
- 2) THERE ARE MANY MORE RETARDED PERSONS CAPABLE OF AND ENGAGING IN SEXUAL INTERCOURSE THAN PAST EXPERTS CONSIDERED POSSIBLE.
- 3) MOST RETARDED CITIZENS ARE ECONOMICALLY POOR AND HAVE NO PARENTS OR PARENTS WHO ARE ECONOMICALLY POOR.
- 4) MANY RETARDED CITIZENS WANT TO BE STERILIZED, ARE CAPABLE OF GIVING INFORMED CONSENT EVEN THOUGH THEY MAY BE UNABLE TO READ OR WRITE OR BE INCOMPETENT TO MANAGE MONEY, AND ARE BEING DENIED THIS RIGHT BECAUSE THEY ARE RETARDED, POOR, AND THE DEPARTMENT OF HEW HAS FROZEN THE USE OF MEDICAL ASSISTANCE FUNDS FOR STERILIZATION PROCEDURES.
- 5) THIS FREEZE DISCRIMINATES AGAINST RETARDED PERSONS WHO ARE ECONOMICALLY POOR OR WHOSE PARENTS ARE ECONOMICALLY POOR IN FAVOR OF THOSE, OR WHOSE PARENTS ARE, ABLE TO PAY,



6) THE IUD, PILL AND 6-MONTH SHOT ARE NOT MEDICALLY FEASIBLE OR REALISTIC FORMS OF BIRTH CONTROL FOR ALL RETARDED FEMALE PERSONS; THEY SHOULD HAVE THE RIGHT NOT TO HAVE CHILDREN AND NOT BE FORCED BY POVERTY TO HAVE UNWANTED CHILDREN OR BE SO FORCED TO TRY UNSUCCESSFULLY OTHER FORMS OF BIRTH CONTROL AND THEREBY HAVE UNWANTED CHILDREN BEFORE HAVING THE RIGHT TO BE STERILIZED.

7) THERE IS A PRESENT DANGER THAT UNDER THE WELL-INTENTIONED GUISE OF PROTECTION, THERE IS NOW AND WILL BE TOO MUCH COURT AND PROFESSIONAL INTERFERENCE AND MEDDLING INTO THE PRIVACY AND LIVES OF ADULT RETARDED CITIZENS.

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION IN ITS RECENT REPORT "MENTAL RETARDATION: CENTURY OF DECISION" ON PAGE 63 STRESSES THE RIGHT OF EQUAL ACCESS TO VOLUNTARY STERILIZATION AND THAT INDIVIDUALS SHOULD NOT BE DENIED STERILIZATION BECAUSE OF THEIR RETARDATION.

IN DISCUSSING INVOLUNTARY STERILIZATION, I BELIEVE WE CAN AGREE THAT:

- 1) NO PERSON, WHETHER PARENT, RELATIVE, GUARDIAN, GOVERNMENT OR INSTITUTION EMPLOYEE, DIRECTOR OF COMMUNITY RESIDENTIAL FACILITY OR PROFESSIONAL SHOULD FORCE OR COERCE A RETARDED PERSON TO BE STERILIZED AGAINST THE LATTER'S WILL IN THE ABSENCE OF A COURT ORDER WHICH EFFECTIVELY SAFEGUARDS THE CONSTITUTIONAL RIGHTS OF THE PERSON.
- 2) NO PERSON WHO IS RETARDED SHOULD BE COERCED BY THE OFFERING OF REWARDS OR PUNISHMENT TO SECURE THE VOLUNTARY CONSENT FOR STERILIZATION.
- 3) NO RETARDED PERSON SHOULD BE DENIED FINANCIAL ASSISTANCE, REFUSED THE RIGHT TO MARRY, OR BE DENIED THE RIGHT TO REMAIN

IN OR BE RELEASED FROM AN INSTITUTION OR COMMUNITY RESIDENTIAL FACILITY UPON CONDITION THAT HE OR SHE BE STERILIZED.

- 4) NO PERSON WHO IS RETARDED SHOULD BE STERILIZED UNDER THE GUISE OF RESEARCH.

ALL OF THE ABOVE SMACK OF THE UNCONSCIONABLE AND HORRIBLE STERILIZATION OF THE JEWS BY HITLER.

HOWEVER, 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 OR WHO ARE BORDERLINE OR MILDLY 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.

YEARS AGO IN MY STATE, WE HAD A HIGHLY SUCCESSFUL CORRECTIONAL PROGRAM FOR DEFECTIVE DELINQUENTS LOCATED IN A STATE PRISON; IT HAD THE LOWEST RECIDIVISM RATE OF ANY CORRECTIONAL FACILITY; THE DEAN OF THE LAW SCHOOL SUCCEEDED IN CLOSING THE FACILITY ON THE GROUND THAT THE RETARDED PERSONS RIGHTS OF DUE PROCESS WERE BEING TECHNICALLY VIOLATED. UNFORTUNATELY, IT WAS CLOSED AND A NEW OR DIFFERENT FACILITY WAS NOT OPENED.

THIRDLY, I AM ALSO CONCERNED ABOUT SOME CIVIL LIBERTARIAN LAWYERS AND MR PROFESSIONALS DESIRE TO ROUTINELY INVOLVE THE COURTS IN ALL STERILIZATIONS OF ALL RETARDED PERSONS. 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 GRAND-CHILDREN, FEAR OF RESPONSIBILITY FOR RAISING AND PAYING FOR SUCH GRANDCHILDREN; UNFOUNDED FEAR THAT 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 OCCASION-  
ALLY 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) SOME ARGUE THAT IN SOME STATES, IT IS OUTRAGEOUS THAT A  
PARENT OR GUARDIAN CAN CONSENT TO STERILIZATION WHEN SUCH ACTION IS  
FORBIDDEN TO THE STATE EVEN WHEN IT ACTS WITH ALL PROPER PROCEDURAL  
SAFEGUARDS.

d) 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?)

e) 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.

f) 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 UNWORKABLE 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. 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 COUNSELLING 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.

g) 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 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. 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.

MY EXPERIENCE AND KNOWLEDGE IS BASED UPON COMMUNICATION WITH MY MILDLY RETARDED MARRIED CLIENTS, MY CONVERSATIONS WITH MANY SOCIAL WORKERS WHO WORK WITH RETARDED MOTHERS, MY STUDY WHILE A MEMBER OF THE PRESIDENTS COMMITTEE ON MR AND MY RECENT EXPERIENCE WITH MY DAUGHTER JANICE WHO WAS RAPED THIS SUMMER.

MY MILDLY RETARDED MARRIED CLIENTS DID NOT WANT CHILDREN, THEY DESIRED AND SECURED STERILIZATION; EACH SPOUSE WANTED TO WORK; EACH FELT INCAPABLE OF RAISING CHILDREN AND THAT THEY DID NOT HAVE THE EMOTIONAL OR FINANCIAL RESOURCES TO HAVE CHILDREN. THEY FELT THEY COULD MAKE THEIR MARRIAGE WORK WITH SOME MONEY MANAGEMENT HELP; THEY ARE MAKING THEIR MARRIAGES WORK; THEY ARE IN FACT RETARDED AND NOT MISDIAGNOSED BY SOME SCHOOL IQ TEST.

*THEY ARE NOT FORCED TO LIVE ON welfare w/ its dehumanizing, dehumanization rules, regulations & interference w/ their PRIVACY.*

FROM MY CONVERSATIONS WITH SOCIAL WORKERS WHO WORK WITH RETARDED MOTHERS, NONE HAVE ADVISED ME OF THEIR FINDING 2 RETARDED PARENTS WHO HAVE A CHILD WHO HAVE BEEN ABLE TO COPE WITH RAISING A CHILD; THESE SOCIAL WORKERS HAVE SEEN MARRIAGES DISSOLVED, MANY CASES OF CHILD ABUSE, CHILD NEGLECT, CHILD INJURY AND CHILD MALNUTRITION. UPON QUESTIONING, THEY HAVE ADVISED OF OCCASIONALLY FINDING A FAMILY WHERE ONE WAS NORMAL AND BRIGHT AND THE OTHER RETARDED WHICH WAS ABLE TO MAKE A SUCCESSFUL MARRIAGE AND RAISE THEIR CHILD WITH REASONABLE SUCCESS.

OUR 24 YEAR OLD MODERATELY RETARDED DAUGHTER, JANICE, WAS RECENTLY RAPED AT A PARK ON THE GROUNDS OF THE FARIBAULT STATE HOSPITAL BY A MILDLY RETARDED MALE RESIDENT; I HOPE THAT JANNY'S AND OUR EXPERIENCE MAY STIMULATE DISCUSSION BY YOU AT THIS CONVENTION. OUR DAUGHTER HAS AN IQ OF 48 TO 50, IS A WARD OF THE COMMISSIONER OF

PUBLIC WELFARE, THOROUGHLY ENJOYS WORKING AS A BUS GIRL AT ANOTHER COTTAGE; HAS HER OWN ROOM; ATTENDS SCHOOL, IS A GIRL SCOUT, SINGS IN THE CHOIR, LEARNED TO PLAY THE ORGAN AT THE INSTITUTION, COMES HOME REGULARLY ON THE BUS FOR FAMILY EVENTS, IS A BEAUTIFUL BED-MAKER, CANNOT MAKE CHANGE, CANNOT WRITE BUT PRINTS HER NAME, CAN DRESS AND CARE FOR HER PERSONAL NEEDS, IS NOT PHYSICALLY ATTRACTIVE, IS SOMEWHAT INTROVERTED, RELATES BETTER TO STAFF THAN HER PEERS, SPEAKS CLEARLY BUT ASKS QUESTIONS RATHER THAN COMMUNICATING HER FEELINGS OR IDEAS. WE ALL LOVE HER VERY MUCH.

THIS WAS JANICE'S FIRST EXPERIENCE WITH SEXUAL INTERCOURSE; THERE WAS NO LOVE OR FRIENDSHIP RELATIONSHIP WITH THE YOUNG MAN; HE PERSUADED HER TO WALK TO THE PARK; HE HIT HER TWICE, PUSHED HER DOWN, TOOK OFF HER CLOTHES AND HAD SEXUAL INTERCOURSE WITH HER: IT HAPPENED DURING THE MIDDLE OF HER MONTHLY CYCLE; WE WERE CALLED THE, NEXT DAY; THE SOCIAL WORKER WHOM I HAVE KNOWN AND TRUSTED FOR MANY YEARS ADVISED THAT THE YOUNG MAN WAS UNDER STATE GUARDIANSHIP AND AT FARIBAULT BECAUSE OF A DIABETIC CONDITION AND INABILITY TO CONTROL HIS EATING WHEN IN THE COMMUNITY; THAT HE WAS SEXUALLY AGGRESSIVE AND SOPHISTICATED, THIS BEING AT LEAST HIS 5TH CONQUEST, THAT HE WAS MISPLACED IN JANNY'S COTTAGE WITH PERSONS OF MUCH LESS CAPABILITY; THAT THE YOUNG LADIES HAD NOT RECEIVED EFFECTIVE SEX EDUCATION AND THAT I SHOULD DECIDE WHETHER TO AUTHORIZE THE INSTITUTION TO ADMINISTER THE MORNING AFTER PILL OR A VAGINAL EVACUATION SINCE SEMEN WAS FOUND. AFTER CALLING TWO MINNEAPOLIS DOCTORS AND RECEIVING CONFLICTING ADVICE, I AUTHORIZED THE MORNING AFTER PILL. THE NEXT DAY JANICE WENT TO A FAIR IN MINNEAPOLIS, THEN ATTENDED CAMP FOR A WEEK AND THERE HAD HER PERIOD AND THEN CAME HOME FOR A VACATION; WHILE HOME SHE HAD NIGHTMARES FOR NO REASON SCRATCHED HER SISTER WHO ACCIDENTALLY BUMPED HER, TOOK AN HOUR TO EAT, WASH HER HANDS AND DRESS, ALL BEING CONTRARY TO PAST CONDUCT.

WE FELT ANGER, GUILT, LIKE WE HAD BEEN KICKED IN THE STOMACH AT FIRST; WE THEN FELT SORRY FOR JANICE. WE PRAYED FOR HER; WE HOPED SHE WOULD NOT BECOME PREGNANT AND THAT WE WOULD NOT HAVE TO ARRANGE FOR AN ABORTION: THERE WAS NO DOUBT IN OUR MINDS OR IN THE MINDS OF THE INDEPENDENT PHYSICIAN, PSYCHOLOGIST AND SOCIAL WORKER THAT JANICE COULD NOT ASSUME THE RESPONSIBILITY OF MOTHERHOOD; WE HAD JANICE EXAMINED BY A MINNEAPOLIS LADY OBSTETRICIAN WHO UPON EXAMINATION AND LEARNING OF JANICE'S HEAVY BLEEDING PROBLEM RECOMMENDED A VAGINAL HYSTERECTOMY LEAVING THE OVARIES; THE DOCTOR IN OUR PRESENCE ASKED JANICE IF SHE WANTED THE OPERATION EVEN THOUGH SHE COULD NEVER HAVE BABIES; JANICE SAID "YES"; THE DOCTOR PREVIOUSLY DESCRIBED THE OPERATION TO HER; AND WE DID DISCUSS THE POSSIBILITY OF A TUBAL LIGATION; JANICE LIKED THE IDEA OF NOT HAVING ANY MORE MENSTRUAL BLEEDING; I TALKED WITH AN EXPERT PSYCHOLOGIST IN MINNEAPOLIS WHO HAD PREVIOUSLY SEEN JANICE AND TESTED HER ON 4 OCCASIONS; HER REPORT WAS IN SUPPORT OF THE OPERATION; I EXPLAINED EVERYTHING TO JANICE AGAIN THAT WEEKEND; SHE DID I BELIEVE UNDERSTAND THAT SHE COULD NOT HAVE BABIES IF SHE HAD THE OPERATION; SHE DID NOT AT ANY TIME OBJECT TO THE OPERATION; SHE SIGNED HER NAME TO THE APPLICATION AT THE PRIVATE HOSPITAL; WE SIGNED AS HER PARENTS; WE DID NOT OFFICIALLY NOTIFY THE INSTITUTION BEFORE SURGERY; WE DID NOT SECURE THE CONSENT OF THE COMMISSIONER OF WELFARE BEFORE SURGERY, ALTHOUGH I HAD PREVIOUSLY ASKED THE SUPERVISOR OF THE DEPARTMENT TO GET THE BALL ROLLING FOR A STERILIZATION AND LEARNED OF THE PROCEDURE TO BE FOLLOWED, (1) SECURE THE CONSENT OF THE COMMISSIONER - (2) SECURE THE PARENTS CONSENT - (3) SECURE A WRITTEN REPORT FROM THE PHYSICIAN RECOMMENDING THE PROCEDURE - (4) SECURE WRITTEN REPORT FROM A PSYCHOLOGIST SKILLED IN MENTAL RETARDATION RECOMMENDING THE PROCEDURE - (5) SECURE WRITTEN REPORT FROM A SOCIAL WORKER APPROVING SAME - (6) THE REPORTS WERE REQUIRED TO AFFIRM THAT STERILIZATION WAS IN THE BEST INTEREST OF THE WARD, THAT THERE WERE NO UNUSUAL MEDICAL RISKS



BE AS EFFECTIVE.

THE DOCTOR ADVISED THAT THE IUD WOULD NOT BE FEASIBLE BECAUSE OF HER HEAVY BLEEDING; THAT THE PILL WOULD NOT BE MEDICALLY FEASIBLE BECAUSE HER MOTHER TOOK THE DRUG DIETHYLSTILBESTEROL (DES) DURING HER PREGNANCY AND THAT THE PILL MIGHT AGGREGATE OR ENHANCE JANICE'S CHANCES OF DEVELOPING VAGINAL CANCER. WE KNEW THE INSTITUTION COULD NOT GUARANTEE THAT JANICE WOULD NOT BECOME PREGNANT: WE KNEW THAT CRACKING THE RED TAPE OF THE DEPARTMENT OF WELFARE MIGHT TAKE MONTHS TO ACCOMPLISH AND EVEN THEN THE COMMISSIONER MIGHT NOT GIVE CONSENT OUT OF POLITICAL FEAR AS OPPOSED TO REASON; I THOROUGHLY CHECKED THE LAW AND PREPARED MY ARGUMENTS; I CERTAINLY BELIEVE THAT WHAT WE DID WAS IN JANICE'S BEST INTERESTS AND WAS LAWFUL, ALTHOUGH I MUST ADMIT THAT A COURT MIGHT DISAGREE. AFTER SURGERY I CALLED THE SUPERINTENDENT OF THE INSTITUTION AND ADVISED HIM OF THE OPERATION AND HE - OFF THE RECORD - COMPLETELY CONCURRED WITH OUR DECISION.

THUS WE DID NOT SECURE THE COMMISSIONER'S CONSENT, DID NOT SECURE A COURT ORDER, DID NOT VOLUNTEER TO THE HOSPITAL THAT JANICE WAS A WARD OF THE STATE AND DID NOT DISCLOSE THAT SHE LIVED AT THE FARIBAULT STATE HOSPITAL, AND DID NOT OFFICIALLY ADVISE THE DOCTOR <sup>of Janice's</sup> ~~GUARDIANSHIP~~ OR THE INSTITUTION OF JANICE'S SURGERY; WE DID NOT ENJOY ANY OF THIS, BUT I ASSURE YOU WE ARE CONVINCED THAT THE OPERATION WAS IN JANICE'S BEST INTERESTS AND I PERSONALLY FEEL THAT THE RISKS OF PREGNANCY WERE MUCH GREATER THAN THE RISKS OF THE OPERATION, THAT IT WOULD HAVE BEEN TOTALLY UNNECESSARY FOR US TO HAVE BEEN FORCED TO GO TO COURT OR SECURE THE CONSENT OF THE COMMISSIONER, WHAT DO YOU THINK? IT TOOK A RAPE FOR US TO QUIT PROCRASTINATING AND DO THAT WHICH WE KNEW SHOULD HAVE BEEN DONE 1 YEARS AGO. JANICE HAS MADE A SPLENDID RECOVERY FROM THE SURGERY. WE HOPE AND BELIEVE THAT SHE WILL RECOVER FROM HER EMOTIONAL UPSET; THE YOUNG MAN HAS BEEN PUT IN ANOTHER COTTAGE WITH MEN ONLY AND IS UNDER BETTER CONTROL AND THE ADVISORY

BOARD OF THE INSTITUTION UPON WHICH I SERVE WILL BE DISCUSSING THIS MATTER MONDAY EVENING; I BELIEVE SOME GOOD WILL RESULT FROM JANICE'S TRAGEDY.

YOUR CHAIRMAN ASKED ME TO COMMENT BRIEFLY UPON GUARDIANSHIP. YOU KNOW BRIEFNESS IS NOT ONE OF MY ASSETS.

THERE ARE TWO PRIMARY ISSUES: (1) SHOULD WE PLACE OUR RETARDED CHILD UNDER FULL GUARDIANSHIP, LIMITED GUARDIANSHIP OR CONSERVATIVE GUARDIANSHIP? (2) WHEN SHOULD THIS BE DONE?

THESE DECISIONS REQUIRE INDIVIDUALIZED ANALYSIS. WE KNOW THAT GUARDIANSHIP PERMITS ONE PERSON TO PROVIDE COMPLETE SUPERVISION OVER AN INDIVIDUAL WHO LACKS ABILITY TO MAKE DECISIONS ON HIS OR HER OWN BEHALF. TO MAKE GUARDIANSHIP AN EFFECTIVE METHOD OF SUPERVISION AND PROTECTION, THE LEGAL RIGHTS OF THE PERSON UNDER GUARDIANSHIP MUST BE REMOVED IN WHOLE OR PART. PRIVATE OR STATE GUARDIANSHIP INVOLVES THE LOSS OF THE RIGHT TO (A) VOTE, (B) MARRY WITHOUT PERMISSION, (C) CONTRACT (EXCEPT FOR NECESSARIES), (D) CHOOSE A RESIDENCE, OR PROGRAM OF EDUCATION, TRAINING OR EMPLOYMENT, (E) SUE OR BE SUED IN YOUR OWN NAME, (F) CONSENT TO SURGERY OR GIVE LEGAL CONSENT ON OTHER MATTERS, (G) BUY AND SELL REAL ESTATE OR PERSONAL PROPERTY.

FOR A MILDLY RETARDED PERSON, AND FOR SOME MODERATELY RETARDED PERSONS, THE LOSS OF ALL OF THOSE RIGHTS WOULD BE UNTHINKABLE, UNLESS THERE WERE A DEMONSTRATED PRESSING NEED FOR PROTECTION WHICH WAS SUBSTANTIALLY MORE IMPORTANT THAN THE LOSS OF SUCH RIGHTS. ON THE OTHER HAND, THE LOSS OF SUCH RIGHTS FOR MOST PROFOUNDLY AND VERY SEVERELY RETARDED PERSONS COULD BE MEANINGLESS AND THE NEED FOR PROTECTION AND SUPERVISION MUCH MORE IMPORTANT.

I HAVE PREPARED IN EXCESS OF 200 ESTATE PLANS FOR PARENTS; IN MOST CASES THE PLAN INCLUDES A TRUST FOR THE BENEFIT OF THE RETARDED

PERSON FOR HIS LIFETIME WHICH GOES INTO EFFECT UPON THE DEATH OF ONE OR BOTH PARENTS. IT PROVIDES THAT UPON THE DEATH OF THE RETARDED PERSON THE REMAINING PRINCIPAL AND INTEREST WILL BE DISTRIBUTED TO SPECIFIC BENEFICIARIES. IN THIS PLAN I GIVE THE INDIVIDUAL TRUSTEES GUARDIANSHIP POWERS. I PROVIDE, HOWEVER, THAT IF GUARDIANSHIP SHOULD IN THE FUTURE BECOME ABSOLUTELY NECESSARY THAT THE INDIVIDUAL TRUSTEE SHALL BECOME THE GUARDIAN, LIMITED GUARDIAN OR CONSERVATORS. MY TRUSTS INCORPORATE FOUR ESSENTIAL DIRECTIONS TO THE TRUSTEES: (1) ALL. INCOME SHALL BE ADDED TO PRINCIPAL, (2) THE TRUSTEES SHALL HAVE SOLE DISCRETION WHETHER TO SPEND OR NOT TO SPEND PRINCIPAL, (3) A STRONG SPENDTHRIFT TRUST CLAUSE IS INCORPORATED, (4) UPON THE DEATH OF THE RETARDED PERSON THERE IS DISTRIBUTION OF THE REMAINING PRINCIPAL AND INCOME TO SPECIFIC BENEFICIARIES.

AS A RESULT OF THOSE FOUR PROVISIONS, THE RETARDED PERSON HAS NO RIGHT TO RECEIVE OR CONTROL THE INCOME OR PRINCIPAL AND AS A RESULT HE DOES NOT HAVE ANY INCOME, HE DOES-NOT HAVE ANY ASSETS, AND HE THEREFORE IS ENTITLED TO RECEIVE SSI, MEDICAL ASSISTANCE, AND OTHER GOVERNMENTAL FINANCIAL ASSISTANCE BENEFITS. THE TRUST IS DESIGNED NOT TO PROVIDE FOR BASIC COSTS OF CARE, BUT RATHER TO PROVIDE THOSE THINGS WHICH THE GOVERNMENTAL BENEFITS CANNOT POSSIBLY PURCHASE.

OUR NEW MINNESOTA PROTECTION ACT PROVIDES FOR A SYSTEM OF STATE GUARDIANSHIP OR CONSERVATORSHIP (THE LATTER IS ACTUALLY LIMITED GUARDIANSHIP), A PROBATE OR COUNTY COURT DETERMINES WHETHER GUARDIANSHIP OR CONSERVATORSHIP IS NEEDED AND IF NEEDED THE TYPE OF SUPERVISION WHICH IS APPROPRIATE. THE COURT RECEIVES BEFORE THE COURT HEARING A COMPREHENSIVE SOCIAL, MEDICAL AND PSYCHOLOGICAL EVALUATION. THE PERSON IS ENTITLED TO AND SHALL HAVE COUNSEL APPOINTED TO REPRESENT HIM. THE PERSON CANNOT BE UNDULY MEDICATED DURING

THE HEARING AND THE HEARING MAY BE HELD IN THE RETARDED PERSON'S HOME.

THE RETARDED PERSON HAS THE RIGHT TO: (A) HAVE THE COMMISSIONER PREPARE AN INDIVIDUALIZED PROGRAM PLAN TO INSURE THAT HIS OR HER THERAPEUTIC, HABILITATIVE AND MEDICAL AND DENTAL NEEDS ARE MET, (B) RECEIVE AN ANNUAL REVIEW OF HIS OR HER PHYSICAL AND MENTAL AND SOCIAL ADJUSTMENT AND PROGRESS, (C) RECEIVE AN ANNUAL REVIEW OF HIS OR HER LEGAL STATUS AND TO HAVE THE STATUS MODIFIED IF NECESSARY TO PROPERLY REFLECT THE PERSON'S PROGRESS, (D) HAVE THE COMMISSIONER EXERCISE THE SUPERVISORY POWERS IN A MANNER WHICH IS LEAST RESTRICTIVE OF THE WARD, CONSERVING AS MANY OF HIS PERSONAL FREEDOMS CONSISTENT WITH THE NEED FOR SUPERVISION, (E) OBTAINING JUDICIAL REVIEW OF DECISIONS BY THE STATE GUARDIAN OR CONSERVATOR WHEN THE RETARDED PERSON OR AN INTERESTED PERSON ACTING IN THE RETARDED PERSON'S BEHALF DISAGREES WITH THAT DECISION, (F) BE FREE OF STERILIZATION UNLESS HE OR SHE GIVES INFORMED CONSENT OR IF UNABLE TO LEGALLY GIVE SUCH CONSENT TO HAVE A COURT REVIEW WHETHER SUCH STERILIZATION IS IN THE PERSON'S BEST INTEREST, (G) TO RECEIVE A FULL DUE PROCESS HEARING PRIOR TO PLACEMENT IN A STATE HOSPITAL.

THE PARENTS HAVE THE RIGHT TO: (A) PARTICIPATE IN PLANNING AND DECISION MAKING FOR THE RETARDED CHILD EVEN IF THE CHILD IS OVER AGE 18, (B) CONSENT OR REFUSE TO CONSENT TO THE STERILIZATION OR OTHER SURGICAL OPERATION FOR THEIR MINOR CHILD, (C) PETITION THE COURT TO MODIFY THE GUARDIANSHIP OR CONSERVATORSHIP OR TO RESTORE THEIR CHILD TO LEGAL CAPACITY OR TO REVIEW DECISION BY THE GUARDIAN.

THE FOURTEENTH AMENDMENT OF THE FEDERAL CONSTITUTION GUARANTEES EVERY CITIZEN EQUAL PROTECTION OF THE LAWS BUT WE DO NOT HAVE THAT FOR THE MENTALLY RETARDED IN ANY STATE IN OUR NATION.

LET US NOW RECAP THE CIVIL, CONSTITUTIONAL AND LEGAL AND MORAL RIGHTS (MANY OF WHICH WILL BECOME LEGAL RIGHTS) BEING DENIED THOUSANDS OF OUR MENTALLY RETARDED CITIZENS. FIRST WE START OUT WITH THREE BASIC PREMISES: (1) RETARDED PEOPLE HAVE THE SAME RIGHTS, LEGAL AND CONSTITUTIONAL, AS EVERY OTHER UNITED STATES CITIZEN, INCLUDING THE RIGHTS OF DUE PROCESS AND EQUAL PROTECTION OF LAWS, (2) RETARDED PEOPLE CAN BE MORE INDEPENDENT, CAN FUNCTION MORE COMPETENTLY AND RESPONSIBLY THAN IS COMMONLY BELIEVED--MENTAL RETARDATION AND INCOMPETENCY ARE NOT SYNONOMOUS, (3) FULL CITIZENSHIP EXERCISED BY RETARDED PERSON IN A COMMUNITY SETTING IS POSSIBLE AND IS IN THE PUBLIC INTEREST.

NOW LET'S CATALOG THESE RIGHTS: (1) THE RIGHT TO HAVE ONE'S MOTHER RECEIVE NUTRITIOUS FOOD AND PRENATAL AND OTHER HEALTH CARE TO MINIMIZE MY CHANCES OF BEING BORN MENTALLY RETARDED OR DEVELOPMENTALLY DISABLED.

(2) THE RIGHT TO EQUAL ACCESS TO QUALITY HEALTH AND SOCIAL SERVICES ADAPTED TO NEED. THIS INCLUDES THE RIGHT TO BE FREE FROM ARBITRARY DENIAL OF LIFESAVING MEDICAL SERVICES, THE RIGHT TO MEDICAL AND MEDICALLY RELATED SERVICES ON AN EQUAL BASIS WITH OTHER CITIZENS, THE RIGHT TO BE PROTECTED FROM UNNECESSARY AND EXPERIMENTAL RESEARCH PROCEDURES, THE RIGHT TO HEALTH SERVICES NECESSARY TO PREVENT OR CONTROL MENTAL RETARDATION, AND THE RIGHT TO HAVE ACCESS TO ALL AVAILABLE SOCIAL SERVICES WHICH FACILITATE THE RETARDED PERSON'S ADJUSTMENT TO SOCIETY AND WHICH FACILITATE HIS DEVELOPMENT.

(3) THE RIGHT TO RESIDENTIAL PROGRAMS AND OTHER SERVICES IN THE SETTING MOST CONDUCIVE TO DEVELOPMENT AND INDEPENDENCE. THIS INCLUDES THE RIGHT TO LIVE WITH PARENTS OR SUBSTITUTE PARENTS, THE RIGHT OF EQUAL ACCESS TO THE VARIETY OF HOUSING OPPORTUNITIES AVAILABLE IN THE COMMUNITY, THIS RIGHT PROHIBITS RESTRICTIVE ZONING, THE RIGHT TO LIVE AND TO RECEIVE SERVICES UNDER THE LEAST RESTRICTIVE

CONDITIONS, THE RIGHT TO BE FREE FROM ARBITRARY COMMITMENT TO A SPECIFIC RESIDENCE SOLELY ON THE BASIS OF MENTAL RETARDATION, THE RIGHT TO BE FREE FROM CUSTODIAL PROGRAMS OFFERING LITTLE OR NO DEVELOPMENTAL OR SUPPORTIVE SERVICES AND THE RIGHT TO APPROPRIATE CARE, TREATMENT AND HABILITATION BASED ON AN INDIVIDUALIZED PROGRAM.

(4) THE RIGHT TO DIGNITY AND LOVE.

(5) THE RIGHT TO PRIVACY.

(6) THE RIGHT TO REASONABLE PROPER FOOD AND CLOTHING AND RECREATION.

(7) THE RIGHT TO MAKE DECISIONS FOR ONE'S SELF, OR AT LEAST TO PARTICIPATE IN THOSE DECISIONS.

(8) THE RIGHT TO EQUAL EDUCATIONAL OPPORTUNITY, WHICH INCLUDES ZERO REJECT PUBLIC EDUCATION, INDIVIDUALIZED PROGRAMS, MOST CONSTRUCTIVE PROGRAM AND SETTING, DUE PROCESS PROTECTION, PERIODIC REVIEW, CENTRALIZED RESPONSIBILITY, AND EXTENDED EDUCATIONAL AGE, COMPENSATORY AND CONTINUING EDUCATION.

(9) THE RIGHT TO EQUAL EMPLOYMENT OPPORTUNITY, WHICH INCLUDES THE RIGHT OF EQUAL ACCESS TO JOB OPPORTUNITIES, THE RIGHT OF EQUAL ACCESS TO JOB TRAINING, THE RIGHT TO WORK IN THE SETTING IN WHICH THE INDIVIDUAL CAN BE MOST PRODUCTIVE, THE RIGHT TO AN ADEQUATE INCOME, THE RIGHT TO BE FREE FROM ARCHITECTURAL OR ORIENTATIONAL BARRIERS IN BUILDINGS AND IN TRANSPORTATION SYSTEMS.

(10) THE RIGHT TO VOTE.

(11) THE RIGHT TO MARRY AND TO BEAR CHILDREN, WHICH INCLUDES THE RIGHT TO BE FREE FROM RESTRICTIONS ON THE SANCTIONS TO MARRY, THE RIGHT TO BE FREE FROM INVOLUNTARY STERILIZATION, THE RIGHT OF EQUAL ACCESS TO VOLUNTARY STERILIZATION, THE RIGHT TO PROCREATE, NURTURE, AND REAR CHILDREN, PROVIDED RETARDED PERSONS HAVE THE

COMPETENCY TO RAISE THEIR CHILDREN AS WOULD ANY OTHER CITIZEN IN THE ABSENCE OF A SPECIFIC JUDICIAL FINDING TO THE CONTRARY.

(12) THE RIGHT TO EQUAL PROTECTION IN THE CRIMINAL JUSTICE SYSTEM, WHICH INCLUDES THE RIGHT TO HAVE QUALIFIED COUNSEL, THE RIGHT TO HAVE POLICE AND OTHER LAW ENFORCEMENT OFFICIALS RECOGNIZE RETARDATION, THE RIGHT TO HAVE LAWYERS WITH SUFFICIENT BACKGROUND IN MENTAL RETARDATION, THE RIGHT TO HAVE EVIDENCE PRESENTED AS TO THE DIMINISHED CAPACITY OF THE ACCUSED PERSON, THE RIGHT TO BE HELD RESPONSIBLE FOR ACTS THAT ARE WITHIN HIS CHOICE, CONTROL AND COMPREHENSION AND THE RIGHT NOT TO BE COMMITTED TO A STATE INSTITUTION FOR THE RETARDED FOR LIFE JUST BECAUSE HE HAS COMMITTED A CRIME AND THE RIGHT TO REHABILITATION.

HOW ARE WE GOING TO PROCURE THESE RIGHTS FOR ALL RETARDED CITIZENS BY THE YEAR 2000?

(1) STRENGTHEN OUR ONE ARC, ADULT AND YOUTH, AT THE LOCAL, STATE AND NATIONAL LEVELS.

(2) SECURE MANY MORE MEMBERS AND MORE FUNDS. WE HAVE SO MUCH TO DO IN CHANGING LAWS, SECURING SERVICES, DEVELOPING MODEL STANDARDS, MONITORING SERVICES.

(3) CHANGE OUR ATTITUDES AS PARENTS TOWARDS OUR RETARDED SONS AND DAUGHTERS FROM A NEGATIVE TO A POSITIVE.

(4) CHANGE THE PUBLIC ATTITUDES FROM THE NEGATIVE TO POSITIVE. TOWARDS THE RETARDED CITIZENS.

(5) EFFECTIVELY MONITOR QUANTITY AND QUALITY OF SERVICE FOR ALL.

(6) REORGANIZE OUR METROPOLITAN ARC'S TO PRESERVE THE ADVANTAGES OF THE STRONG CENTRAL ORGANIZATION, BUT TO SUBDIVIDE INTO SMALLER UNITS, GRASS-ROOTS UNITS, WHICH INVOLVE MANY MORE OF OUR MEMBERS AND WHICH INVOLVE POVERTY, MINORITY AND YOUNG PERSONS WITH FULL MEMBERSHIP

RIGHTS. SOME UNITS SHOULD BE LOCATED IN EVERY SUBURB AND EVERY WARD OR SCHOOL DISTRICT AND I WILL NEVER ACCEPT THE PROPOSITION THAT OUR INDIAN AND BLACK AMERICAN FRIENDS WILL NOT JOIN WITH US IN THIS IMPORTANT SERVICE.

(7) ASSURE THAT THE LEGAL RIGHTS OF ALL RETARDED CITIZENS ARE NOT ONLY ESTABLISHED BY LAW BUT ENFORCED FOR EACH.

(8) DEVELOP TRUE CITIZEN ADVOCACY AND SEE TO IT THAT THERE IS AT LEAST ONE FRIEND FOR EACH RETARDED CITIZEN.

(A) START WITH ME AS A PARENT, MAKE CERTAIN THAT PARENTS OF CHILDREN THAT ARE IN INSTITUTIONS, AND THOSE LIVING IN THE COMMUNITY, DEVELOP A HEALTHY UNDERSTANDING OF BOTH.

(B) INVOLVE OUR CHILDREN AND OTHER RELATIVES.

(C) INVOLVE OUR FRIENDS.

(D) INVOLVE THE LOCAL, STATE AND NATIONAL NARC.

(E) INVOLVE CITIZENS OF OTHER CLUBS AND ORGANIZATIONS.

(F) DEVELOP TEAM ADVOCACY WITH PROFESSIONALS AND RELATIVES.

(G) ENCOURAGE THE RETARDED PERSON TO BE AN ADVOCATE FOR HIMSELF WHEREVER POSSIBLE.

(H) PROMOTE EFFECTIVE COMMUNICATION BETWEEN THE OLD AND THE YOUNG PARENTS, OLD AND YOUNG PROFESSIONALS, IN ORDER TO DEVELOP PLANS WHICH ARE APPROPRIATE FOR EACH INDIVIDUAL.

(9) ATTEMPT TO INTELLIGENTLY WORK WITH PROFESSIONALS, JUDGES, LEGISLATORS, DOCTORS, AND OTHERS IN ORDER TO FIND SOLUTIONS TO PROBLEMS.

(10) ATTEMPT TO FIND NEW WAYS AND MEANS OF MORE EFFICIENTLY AND WITH COST EFFECTIVENESS PROVIDE NECESSARY SERVICES AND PROGRAMS FOR ALL RETARDED CITIZENS IN NEED.



IN CONCLUSION - WE CAN DO IT; WE MUST DO IT; WHEN WE DO IT WE WILL NO LONGER FEEL LIKE POOR, BLACK, BROWN OR WHITE UNEMPLOYED, RETARDED, OR MENTALLY ILL, OR PHYSICALLY DISABLED PERSONS WHO WANT TO WORK, OR AS A DOPE ADDICT OR ALCOHOLIC WHO WANTS TO KICK THE HABIT, OR AN EX-CON WHO WANTS TO GO STRAIGHT, OR AN OTHERWISE TUNED-OUT AMERICAN. RATHER, WE WILL ALL BE TUNED-IN AMERICANS HAPPY AND PROUD THAT OUR HANDICAPPED CITIZENS, OUR LEAST FORTUNATE CITIZENS, HAVE THE SAME LEGAL RIGHTS AS WE, HAVE THE SAME OPPORTUNITY FOR LIFE, LIBERTY AND THE PURSUIT OF HAPPINESS AS WE, THAT THEY RECEIVE THE SAME OPPORTUNITY FOR SERVICES AND PROGRAMS AND DIGNITY AS WE.

THANK YOU. GOD BLESS YOU ALL. HAVE AN EXCITING AND PRODUCTIVE CONVENTION.