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AIDS AND AMERICAN VALUES

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I'M SURE YOU'VE HEARD A GREAT DEAL ABOUT THE EPIDEMIC OF AIDS SO FAR -- ESPECIALLY THE BIOMEDICAL INFORMATION -- SO I HAVE CHOSEN TO SPEND THE NEXT FEW MOMENTS SHARING WITH YOU A NUMBER OF OTHER, <u>NON-MEDICAL CONCERNS THAT HAVE BEEN BROUGHT TO MY ATTENTION</u>, AS I HAVE TRAVELED ABOUT THIS COUNTRY AND ALSO OVERSEAS.

FIRST, LET ME EMPHASIZE THAT THE THREE ASPECTS OF AIDS THAT COLOR EVERYTHING DONE AND SAID ABOUT THE DISEASE ARE...ONE, THAT IT IS <u>STILL A MYSTERY</u>...TWO, THAT IT IS <u>FATAL</u>...AND THREE, THAT YOU GET AIDS CHIEFLY BY DOING THINGS THAT <u>THE MAJORITY OF PEOPLE DON'T DO</u> <u>AND DON'T LIKE</u>. THESE THREE ASPECTS OF THE AIDS EPIDEMIC PRESENT THE PEOPLE OF THE UNITED STATES WITH AN EXTREMELY DIFFICULT AND COMPLEX TEST OF OUR NATIONAL CHARACTER. IN SOME WAYS THE SCIENTIFIC ISSUES PALE IN COMPARISON TO THE HIGHLY SENSITIVE ISSUES OF LAW, ETHICS, ECONOMICS, MORALITY, AND SOCIAL COHESION THAT ARE BEGINNING TO SURFACE.

I BELIEVE WE'RE ALREADY AT A SENSITIVE STAGE CONCERNING THE ETHICAL FOUNDATION OF HEALTH CARE ITSELF.

DESPITE THE SENSIBLE AND RATHER ELEMENTARY GUIDELINES FROM C.D.C. TO THE HEALTH PROFESSIONS, WE STILL HEAR -- EVERY DAY -- OF PHYSICIANS, DENTISTS, NURSES, AND OTHER HEALTH PERSONNEL WHO REFUSE TO TREAT PERSONS WITH AIDS OR EVEN PERSONS WHOM THEY <u>SUSPECT</u> OF HAVING AIDS. THEY ARE AFRAID OF CATCHING THE DISEASE THEMSELVES. THAT'S CERTAINLY UNDERSTANDABLE. EQUALLY UNDERSTANDABLE IS THE FACT THAT IT IS VERY <u>UN</u>LIKELY THAT A HEALTH WORKER WILL CATCH THE DISEASE AT ALL.

THUS FAR, OF THE 5 MILLION PERSONS IN SOME KIND OF HEALTH WORK IN THIS COUNTRY, ONLY 10 HAVE CONTRACTED AIDS ON THE JOB. IN ALMOST EVERY CASE, THE INDIVIDUAL SIMPLY DID NOT FOLLOW THE ROUTINE INSTRUCTIONS FOR SELF-PROTECTION THAT THE CENTERS FOR DISEASE CONTROL PUBLISHED OVER A YEAR AGO. LET ME QUICKLY ADD THAT THIS REJECTION OF AIDS PATIENTS IS NOT CHARACTERISTIC OF THE HEALTH PROFESSIONALS BY ANY MEANS. ON THE CONTRARY, THE OVERWHELMING MAJORITY OF MY COLLEAGUES HAVE PROVIDED -- AND <u>CONTINUE</u> TO PROVIDE -- QUALITY, COMPASSIONATE CARE TO PERSONS WITH EVERY KIND OF ILLNESS...INCLUDING AIDS.

BUT THE GOOD CONDUCT OF THE MAJORITY DOES NOT IN ANY WAY RELEASE US FROM FACING THE UN-PROFESSIONAL CONDUCT OF A FEARFUL AND IRRATIONAL MINORITY.

WHAT SHOULD WE DO ABOUT THAT? I SUBMIT THAT IT'S AN IMPORTANT QUESTION, BECAUSE HEALTH CARE IN THIS COUNTRY HAS ALWAYS BEEN PREDICATED ON THE ASSUMPTION THAT -- SOMEHOW -- <u>EVERYONE</u> WILL BE CARED FOR AND <u>NO ONE</u> WILL BE TURNED AWAY. AS A PHYSICIAN AND AN AMERICAN, I'M PROUD TO BE PART OF A TRADITION OF CARE THAT WILL NOT ABANDON THE SICK AND THE DISABLED... WHOEVER THEY ARE.

HENCE, THE REPORTS OF A FEW PHYSICIANS AND OTHERS WITHHOLDING CARE FROM PERSONS WITH AIDS ARE, THEREFORE, EXTREMELY SERIOUS. SUCH CONDUCT THREATENS THE VERY FABRIC OF HEALTH CARE IN THIS COUNTRY.

BUT THIS ISSUE HAS YET ANOTHER WRINKLE OR TWO.

I'M TOLD THAT THOSE HOSPITALS WITH NATIONAL REPUTATIONS FOR PROVIDING CARE FOR AIDS PATIENTS ARE NOW BEING BY-PASSED BY MANY MEDICAL AND NURSING STUDENTS LOOKING FOR A RESIDENCY, AN INTERNSHIP, OR A PRACTICUM TO COMPLETE THEIR PROFESSIONAL TRAINING. IN ADDITION, MANY <u>NON</u>-AIDS PATIENTS -- ESPECIALLY THOSE WITH GOOD INSURANCE COVERAGE -- ARE ASKING THEIR PHYSICIANS TO CHECK THEM INTO HOSPITALS THAT DO <u>NOT</u> HAVE MANY -- OR <u>ANY</u> -- AIDS PATIENTS.

I THINK THIS IS A SERIOUS MATTER BECAUSE THE ACTUAL DIRECT IMPACT OF AIDS THUS FAR ON OUR HOSPITAL SYSTEM IS QUITE SMALL...BUT THIS INDIRECT IMPACT CAN BE QUITE LARGE...DISPROPORTIONATELY SO. IT IS AN IMPACT THAT COULD WELL LEAD TO THE DEVELOPMENT OF DE FACTO MEDICAL GHETTOS FOR AIDS PATIENTS.

HOW CAN WE PREVENT THAT FROM HAPPENING? WE NEED SOME ANSWERS BEFORE THIS DEADLY VIRUS FURTHER WEAKENS THE ETHICS OF MEDICAL PRACTICE IN THE UNITED STATES. A RELATED ISSUE IS THE COST OF CARE FOR AIDS PATIENTS. THOSE COSTS ARE NOW RUNNING AT ABOUT \$2 BILLION A YEAR. BY 1991, WE ANTICIPATE THE ANNUAL BILL FOR PATIENT CARE FOR AIDS VICTIMS WILL RANGE ANYWHERE FROM A LOW OF \$8 BILLION TO A HIGH OF \$16 BILLION.

WHO SHOULD PAY THAT?

RIGHT NOW, THE AMERICAN TAXPAYER IS COVERING ABOUT 25 PERCENT OF THAT COST, POSSIBLY MORE. IS THAT FAIR?

AS YOU KNOW, WE HAVE A MIXED SYSTEM OF SUPPORT FOR HEALTH CARE IN THIS COUNTRY: PRIVATE METHODS OF PAYMENT EXIST SIDE-BY-SIDE WITH PUBLICLY SUPPORTED SYSTEMS OF REIMBURSEMENT FOR CARE. THERE IS, HOWEVER, A CURIOUS TWIST TO THIS PARTICULAR QUESTION.

FOR EXAMPLE, THE AMERICAN TAXPAYER SUPPORTS MATERNAL AND CHILD HEALTH PROGRAMS, AS WELL AS PROGRAMS FOR ALCOHOLICS, DRUG ADDICTS, AND SYPHILITICS.

THOSE PROGRAMS AREN'T REALLY EXPENSIVE. IN ADDITION, THEY ARE GEARED TO BRING -- OR BRING <u>BACK</u> -- MEN, WOMEN, AND CHILDREN TO A STATE OF GOOD HEALTH.

BUT AIDS IS QUITE DIFFERENT. HEALTH AND MEDICAL CARE FOR AN AIDS PATIENT IS VERY EXPENSIVE. THE <u>JOURNAL OF THE AMERICAN MEDICAL</u> <u>ASSOCIATION</u> JUST PUBLISHED A STUDY INDICATING THAT THE AVERAGE INPATIENT COST PER AIDS PATIENT PER YEAR IS \$20,320. AND WHAT'S THE OUTCOME? AFTER CONSUMING THREE TO FOUR YEARS' WORTH OF COSTLY MEDICAL CARE AND SOCIAL SERVICES...THE AIDS PATIENT DIES.

SO WE MUST ASK THIS QUESTION: AS THE AIDS CASE-LOAD CLIMBS AND THE COSTS RISE, WILL THE AMERICAN PEOPLE CONTINUE TO SUPPORT SUCH CARE? WILL THEY ASK FOR RELIEF? OR WILL THEY SUPPORT ONLY SECOND-CLASS CARE FOR AIDS PATIENTS?

HOW SHOULD WE RESPOND TO THAT POSSIBILITY? IT'S A VERY TROUBLING QUESTION FOR AMERICAN MEDICINE AND AMERICAN DOMESTIC PUBLIC POLICY. ANOTHER ISSUE THAT HAS ARISEN QUITE FAST OVER THE PAST YEAR OR SO IS THE ISSUE OF INDIVIDUAL PRIVACY <u>versus</u> THE NEED TO PROTECT THE COMMUNITY FROM DANGER.

NEITHER SIDE OF THIS EQUATION REQUIRES AN ABSOLUTE RESPONSE. BUT HOW MUCH LEEWAY DO WE REALLY HAVE, AS A FREE YET RESPONSIBLE PEOPLE?

ANOTHER WAY OF PUTTING THAT IS TO ASK, "HOW MUCH RISK CAN THE COMMUNITY TOLERATE IN ORDER TO PRESERVE THE RIGHTS OF INDIVIDUALS?"

THIS, OF COURSE, IS THE HEART OF THE DEBATE OVER CONFIDENTI-ALITY IN RECORDS. FOR THOSE OF YOU WHO DON'T KNOW ABOUT IT, I WILL ADD THAT CONFIDENTIALITY HAS BEEN A LONG-STANDING PRACTICE IN PUBLIC HEALTH WORK. THE PROMISE OF CONFIDENTIALITY HELPS US GET A GREAT DEAL OF SENSITIVE, HEALTH-RELATED INFORMATION FROM THE INDIVIDUAL. WITHOUT SUCH A SYSTEM, THIS COUNTRY WOULD NEVER HAVE SUCCEEDED IN CONTAINING MOST INFECTIOUS DISEASES, AS WE HAVE DONE.

HOWEVER, NO PREVIOUS DISEASE HAS BEEN AT ONCE SO <u>MYSTERIOUS</u>, SO <u>FATAL</u>, AND SO <u>RESISTANT TO THERAPY AND PREVENTION</u>.

THOSE OF US IN PUBLIC HEALTH BELIEVE THAT THE ASSURANCE OF TOTAL CONFIDENTIALITY IS THE KEY TO HAVING POTENTIAL -- AND ACTUAL -- CARRIERS OF THE AIDS VIRUS PRESENT THEMSELVES FOR VOLUNTARY TESTING AND COUNSELING. BUT AGAIN, WE MUST BE CAREFUL NOT TO TAKE AN ABSOLUTIST'S POSITION. LET ME GIVE YOU A RECENT EXAMPLE INVOLVING THE WORK OF MY OWN OFFICE.

EARLIER THIS YEAR I WAS ASKED BY THE DEPARTMENT OF JUSTICE TO LOOK AT THE ISSUE OF CHILD SEXUAL ABUSE. WITH THE HELP OF A NUMBER OF HEALTH AND LAW ENFORCEMENT EXPERTS FROM AROUND THE COUNTRY, I'VE BEEN DEVELOPING A DRAFT STATEMENT TO THE HEALTH PROFESSIONS GENERAL-LY, WITH SPECIAL ATTENTION TO THE CARE AND TREATMENT OF VICTIMS.

AMONG THE RECOMMENDATIONS IS ONE THAT ADVISES HEALTH PERSON-NEL TO ADMINISTER A NUMBER OF TESTS...INCLUDING A TEST FOR THE PRESENCE OF AIDS. IN OTHER WORDS, WE BELIEVE A HEALTH WORKER SHOULD CHECK TO SEE IF THE PERPETRATOR PASSED THE AIDS VIRUS ON TO THE CHILD VICTIM DURING A SEXUAL ATTACK. WE NEED TO KNOW THAT BECAUSE, FOR EXAMPLE, A CHILD WITH THE AIDS VIRUS SHOULD NOT RECEIVE THE ROUTINE SERIES OF VACCINATIONS THAT NEARLY EVERY CHILD IN AMERICA NOW GETS. INDEED, FOR SOME CHILDREN WITH AIDS, <u>VACCINATION ITSELF</u> COULD BE LIFE-THREATENING.

NATURALLY, PARENTS SHOULD BE TOLD IF THEIR CHILD IS SERO-POSITIVE. AND THE FAMILY PHYSICIAN SHOULD BE TOLD, ALSO.

BUT SHOULD THE SCHOOL BE TOLD? SHOULD THE CHILD'S RELIGIOUS CONGREGATION BE TOLD? IN OTHER WORDS, HOW MUCH OF THE PUBLIC HAS A TRUE "NEED TO KNOW" ABOUT THE RESULTS OF A CHILD'S TEST FOR AIDS? I MAINTAIN THAT THE ISSUE OF CONFIDENTIALITY WOULD NEVER HAVE COME UP, IF IT WERE NOT FOR A NUMBER OF INSTANCES IN WHICH PERSONS KNOWN TO HAVE AIDS WERE FIRED FROM THEIR JOBS ...LOST THEIR INSUR-ANCE...WERE EVICTED FROM HOUSING...WERE SENT HOME FROM SCHOOL...AND SO ON.

SUCH REACTIONS ARE IRRATIONAL, UNFAIR, AND DISCRIMINATORY. WELL, WHAT SHOULD WE DO ABOUT THEM? HOW CAN WE DEAL WITH THESE INCLINATIONS TOWARD DISCRIMINATION?

SOME PEOPLE ARGUE THAT IT IS NOT DISCRIMINATORY TO DENY HOUSING OR MEDICAL CARE OR ANY OTHER ESSENTIAL SERVICE TO A PERSON WHO CONTRACTED AIDS WHILE SHOOTING DRUGS OR ENGAGING IN SODOMY. BUT THE GREAT MARCH OF PUBLIC POLICY FOR OVER A CENTURY IN THIS COUNTRY HAS BEEN TO REDUCE OR ELIMINATE ALTOGETHER THE CRITERIA FOR ELIGIBILITY TO RECEIVE ESSENTIAL PUBLIC SERVICES.

IS AIDS GOING TO BE THE EXCEPTION? IF SO, WHY?

FINALLY -- AND PROBABLY MOST IMPORTANT OF ALL -- WE SEE MORE EVIDENCE EVERY DAY THAT THIS DISEASE IS BECOMING THE PARTICULAR SCOURGE OF PEOPLE WHO ARE YOUNG, BLACK, AND HISPANIC.

HOW TRAGIC FOR THEM.

AND HOW TRAGIC FOR AMERICA.

THIS COUNTRY IS ONLY NOW EMERGING FROM TWO DECADES OF TURMOIL, DURING WHICH WE TRIED TO CORRECT THE SOCIAL INJUSTICES OF THE PAST. WE HAVE FINALLY EXTENDED TO ALL AMERICANS -- REGARDLESS OF RACE, COLOR, CREED, ETHNIC ORIGIN, RELIGION, AGE, OR SEX -- THE BIRTHRIGHT OF FREEDOM THAT IS THEIRS.

WILL THE DISEASE OF AIDS -- BY ITSELF -- REVERSE THIS TREND OF HISTORY? WE HOPE AND PRAY THAT IT WILL NOT.

BUT HOPES AND PRAYERS MAY NOT BE ENOUGH. WE WILL NEED COURAGEOUS LEADERSHIP AT ALL LEVELS OF GOVERNMENT AND THROUGHOUT OUR SOCIAL AND POLITICAL INSTITUTIONS TO REINFORCE THOSE HOPES AND PRAYERS. HOW CAN YOU...AND I...AND <u>EVERY</u> AMERICAN INSURE THAT OUR COUNTRY WILL NOT RETURN IN FEAR AND HATRED TO THE WAYS OF A SHAMEFUL PAST?

THE PRESIDENT HAS SAID THAT WE MUST COME TOGETHER TO FIGHT THIS DISEASE WITH EVERYTHING AT OUR COMMAND. BUT WE MUST <u>NOT</u> FIGHT THE PEOPLE WHO HAVE IT.

CAN WE DO THAT? CAN WE, FOR EXAMPLE, REMAIN COLOR-BLIND IN THIS WAR AGAINST AIDS? HOW DO WE MAKE SURE WE CAN?

THESE AND OTHER ISSUES LIE BEFORE OUR COUNTRY...AND BEFORE THE WORLD. LET ME TALK ABOUT THAT FOR A MINUTE.

AMONG MY OTHER JOBS IS THAT OF DIRECTOR OF THE OFFICE OF INTERNATIONAL HEALTH. IN THAT ROLE I HAVE MANY OCCASIONS TO SPEAK WITH HEALTH MINISTERS OF OTHER NATIONS ON THEIR VISITS HERE OR ON MY TRAVELS OVERSEAS. AND I AM CONSTANTLY REMINDED OF THE EXTENT TO WHICH THE UNITED STATES IS A BEACON OF <u>GOOD SENSE</u> AND <u>GOOD SCIENCE</u> FOR THE REST OF THE WORLD.

AND TODAY ESPECIALLY, THE WORLD SORELY NEEDS US.

AS OF AUGUST, THE REPORTED AIDS CASE-LOAD IN COUNTRIES OTHER THAN THE UNITED STATES HAD REACHED 14,600. THAT SEEMS TO BE A VERY LOW FIGURES. WE HAVE EVERY REASON TO BELIEVE THAT IT IS SO LOW BECAUSE OF SEVERE UNDER-REPORTING OF THE DISEASE OF AIDS. IN AFRICA, FOR EXAMPLE, WHERE THE DISEASE IS RAGING AMONG THE HETEROSEXUAL POPULATION, OVER A DOZEN AFRICAN NATIONS REPORT NO CASES OF AIDS AT ALL...ZERO. OBVIOUSLY THAT'S A POLITICAL AND NOT AN EPIDEMIOLOGICAL FACT OF THEIR NATIONAL LIFE.

DESPITE SUCH NON-REPORTS, THE WORLD HEALTH ORGANIZATION NOTES THAT THE NUMBER OF AIDS VICTIMS IS CLIMBING STEEPLY AND THAT, OVER THE NEXT 5 YEARS, THE WORLD COULD ADD ANYWHERE FROM ANOTHER HALF-MILLION TO <u>3 MILLION</u> NEW CASES OF AIDS.

AND RIGHT HERE LET ME EMPHASIZE A POINT THAT WE MUST NOT FORGET: <u>DISEASE KNOWS NO NATIONAL BOUNDARIES</u>. THE DISEASE OF AIDS ITSELF APPARENTLY CAME TO THESE SHORES FROM AFRICA BY WAY OF THE CARIBBEAN OR OF CANADA. CLEARLY PART OF OUR SUCCESS IN CONTAINING THE DISEASE <u>HERE</u> WILL DEPEND ON HOW WELL IT IS CONTAINED <u>ELSEWHERE</u>.

SO WE MUST STAND TOGETHER WITH OUR NEIGHBORS ON THIS TINY PLANET.

YES, AIDS IS A TRAGEDY FOR EACH PERSON WHO IS INFECTED. BUT IT IS ALSO A TRAGEDY FOR HUMANITY ITSELF. THEREFORE, WE MUST BE CONCERNED NOT ONLY WITH THE DEATH OF THE <u>FLESH</u> OF THOSE STRICKEN WITH AIDS, BUT ALSO WITH THE DEATH OF THE <u>SPIRIT</u> OF THOSE WITH<u>OUT</u> AIDS WHO LIVE IN FEAR AND ANGER.

THANK YOU.

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