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<u>Address</u>

Ву

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OF THE

U. S. PUBLIC HEALTH SERVICE
U. S. DEPARTMENT OF HEALTH AND HUMAN SERVICES



PRESENTED TO THE PRESIDENT'S COMMSSION ON AIDS

WASHINGTON, D.C.

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DR, MAYBERRY AND MEMBERS OF THE COMMISSION...

MY COLLEAGUES HAVE THUS FAR TOUCHED UPON A RANGE OF EPIDEMIOLOGICAL AND BIOMEDICAL ISSUES REGARDING THE PANDEMIC OF AIDS, AND I SEE NO REASON TO GO OVER THAT MATERIAL AGAIN.

INSTEAD, I WOULD LIKE TO SPEND THE NEXT FEW MOMENTS SHARING WITH YOU A NUMBER OF CONCERNS THAT HAVE BEEN BROUGHT TO MY ATTENTION, AS I HAVE TRAVELED ABOUT THIS COUNTRY AND ALSO OVERSEAS.

FIRST, LET ME EMPHASIZE AGAIN 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</u>
DO AND DON'T LIKE.

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 PURELY 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 ARE 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.

LET ME QUICKLY ADD THAT THIS IS NOT CHARACTERISTIC OF 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 DYING OF 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? IT'S AN IMPORTANT QUESTION,
BECAUSE HEALTH CARE IN THIS COUNTRY HAS ALWAYS BEEN PREDICATED ON
THE ASSUMPTION THAT -- SOMEHOW -- EVERYONE WILL BE CARED FOR AND NO
ONE 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.

WHAT SHALL WE DO TO 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: WHO SHOULD BEAR THAT COST?

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.

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

ALL SUCH PROGRAMS ARE PART OF OUR GOVERNMENT'S TOTAL COMMIT-MENT TO PROVIDE FOR "THE GENERAL WELFARE" OF THE AMERICAN PEOPLE. AS THE CONSTITUTION INSTRUCTS.

BUT THOSE PROGRAMS ARE NOT REALLY EXPENSIVE. IN ADDITION, THEY ARE GEARED TO BRING -- OR BRING BACK -- MEN, WOMEN, AND CHILDREN TO A STATE OF GOOD HEALTH.

ON THE OTHER HAND, AIDS IS PROVING TO BE VERY EXPENSIVE. THEN, AFTER CONSUMING TENS OF THOUSANDS OF DOLLARS WORTH OF MEDICAL CARE AND SOCIAL SERVICES...THE AIDS PATIENT DIES.

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

HOW SHOULD WE RESPOND TO THAT POSIBILITY? IT IS A VERY TROUBLING QUESTION FOR DOMESTIC PUBLIC POLICY.

OTHERS HAVE ALREADY MENTIONED THE ISSUE OF INDIVIDUAL PRIVACY VERSUS THE NEED TO PROTECT THE COMMUNITY FROM DANGER. NEITHER SIDE OF THE QUESTION REQUIRES AN ABSOLUTE RESPONSE. BUT HOW MUCH LEEWAY DO WE HAVE. AS A FREE BUT REPSONSIBLE PEOPLE? HOW MUCH RISK CAN THE COMMUNITY TOLERATE IN ORDER TO PRESERVE THE RIGHTS OF INDIVIDUALS.

THIS IS THE HEART OF THE DEBATE OVER CONFIDENTIALITY IN RECORDS. IT HAS BEEN A LONG-STANDING PRACTICE IN PUBLIC HEALTH TO GET AS MUCH SENSITIVE, HEALTH-RELATED INFORMATION AS POSSIBLE FROM THE INDIVIDUAL, IN EXCHANGE FOR A GUARANTEE OF CONFIDENTI- ALITY. WITHOUT SUCH A SYSTEM, WE WOULD NEVER HAVE SUCCEEDED IN CONTAINING MOST INFECTIOUS DISEASES, AS WE HAVE DONE.

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

WE 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 OF TAKING AN ABSOLUTE 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 GENERALLY REGARDING THE CARE AND TREATMENT OF VICTIMS.

AMONG THE RECOMMENDATIONS IS ONE THAT ADVISES HEALTH PERSONNEL 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 TO THE CHILD
VICTIM DURING THE SEXUAL ATTACK.

WE NEED TO KNOW THAT BECAUSE A CHILD WITH THE AIDS VIRUS SHOULD NOT RECEIVE THE ROUTINE SERIES OF VACCINATIONS THAT NEARLY EVERY CHILD IN AMERICA NOW GETS. FOR THE CHILD WITH AIDS, VACCINATION ITSELF COULD BE LIFE-THREATENING.

NATURALLY THE PARENTS SHOULD BE TOLD IF THEIR CHILD IS SERO-POSITIVE. AND THE FAMILY PHYSICIAN, ALSO, IF THERE IS ONE. BUT SHOULD THE SCHOOL BE TOLD? SHOULD THE CHILD'S RELIGIOUS CONGREGATION BE TOLD? HOW MUCH OF THE PUBLIC HAS A "NEED TO KNOW" WHETHER OR NOT THE CHILD IS SEROPOSITIVE?

I HAVE MAINTAINED THAT THE ISSUE OF CONFIDENTIALITY WOULD NEVER HAVE COME UP, HAD IT NOT BEEN FOR A NUMBER OF INSTANCES IN WHICH PERSONS KNOWN TO HAVE AIDS HAVE BEEN FIRED FROM THEIR JOBS ...HAVE LOST THEIR INSURANCE...HAVE BEEN EVICTED FROM HUOSING... HAVE BEEN SENT HOME FROM SCHOOL...AND SO ON.

THESE REACTIONS HAVE BEEN IRRATIONAL, UNFAIR, AND DISCRIM-INATORY. WHAT SHOULD WE DO ABOUT IT? HOW CAN WE DEAL WITH THESE INCLINATIONS TOWARD DISCRIMINATION?

SOME PEOPLE HAVE ARGUED 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 OVER THE PAST CENTURY IN THIS COUNTRY HAS BEEN TO REDUCE OR ELIMINATE ALTOGETHER CRITERIA FOR ELIGIBILITY TO RECEIVE ESSENTIAL PUBLIC SERVICES.

IS AIDS THE EXCEPTION? AND 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 TUR-MOIL, DURING WHICH WE HAVE 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 THIS COMMISSION CONTRIBUTE TO THAT LEADERSHIP? 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.

AS THE PRESIDENT HAS SAID, WE MUST COME TOGETHER AND FIGHT THIS DISEASE WITH EVERYTHING AT OUR COMMAND. BUT WE MUST NOT BE THE ENEMIES OF THE PEOPLE WHO HAVE IT.

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

THESE AND OTHER ISSUES LIE BEFORE YOU. AS I INDICATED EARLIER,
THEY ARE EVERY BIT AS COMPLEX AS THE PURELY SCIENTIFIC ISSUES ARE.
AND THEY NEED EVERY BIT AS MUCH OF YOUR BEST THINKING AND
LEADERSHIP.

IN MY ROLE AS DIRECTOR OF THE OFFICE OF INTERNATIONAL HEALTH, I HAVE HAD MANY OCCASIONS TO SPEAK WITH THE HEALTH MINISTERS OF OTHER NATIONS AND I AM CONSTANTLY REMINDED OF THE EXTENT TO WHICH THE UNITED STATES IS A BEACON OF GOOD SENSE AND GOOD SCIENCE 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 HAS REACHED 14,600. WE HAVE EVERY REASON TO BELIEVE THAT SUCH A FIGURE REPRESENTS VERY LOW UNDER-REPORTING OF THE DISEASE.

HOWEVER, THE WORLD HEALTH ORGANIZATION NOTES THAT THE NUMBERS ARE CLIMBING STEEPLY AND THAT, OVER THE NEXT 5 YEARS, THE WORLD COULD ADD ANYWHERE FROM ANOTHER HALF-MILLION TO 3 MILLION NEW CASES OF AIDS.

THIS IS ONE MAJOR REASON WHY THE PRESIDENT HAS ASKED THE CONGRESS TO APPROPRIATE THE FULL U.S. CONTRIBUTION TO THE UNITED NATIONS, AND ESPECIALLY TO THE WORLD HEALTH ORGANIZATION.

DISEASE KNOWS NOT BORDERS. THE DISEASE OF AIDS ITSELF
APPARENTLY CAME TO THESE SHORES FROM AFRICA BY WAY OF THE
CARIBBEAN. AND CLEARLY PART OF OUR SUCCESS IN CONTAINING THE
DISEASE HERE WILL DEPEND ON HOW WELL IT IS CONTAINED ELSEWHERE.

IT WILL BE TERRIBLY SELF-DEFEATING, IF THE UNITED STATES DOES NOT PAY ITS FULL ASSESSMENT TO THE UNITED NATIONS AND THUS ENABLE THE WORLD HEALTH ORGANIZATION TO BE AN EFFECTIVE WORLD LEADER IN THE FIGHT AGAINST AIDS.

HERE, AGAIN, WE MUST MAKE THE CHOICE THAT IS ETHICALLY

CORRECT. WE MUST STAND WITH OUR NEIGHBORS ON THIS TINY PLANET.

AIDS IS A TRAGEDY FOR EACH PERSON WHO IS INFECTED. BUT IT IS ALSO A

TRAGEDY FOR HUMANITY ITSELF.

THESE ARE A FEW OF THE THOUGHTS AND CONCERNS THAT HAVE RISEN IN OUR DISCUSSIONS OVER THE PAST 6 YEARS, BUT MOST INSISTENTLY OVER THE PAST YEAR OR SO.

I HOPE YOU WILL INVESTIGATE THESE ISSUES AS WELL AND COME FORWARD WITH GUIDANCE AND GOOD COUNSEL WHEN YOUR DELIBERATIONS ARE OVER.

BEST WISHES...AND THANK YOU.

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