

## AIDS AND THE SOCIAL ORDER

Ву

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(GREETINGS TO HOSTS, GUESTS, FRIENDS, ETC.)

I APPRECIATE THIS OPPORTUNITY TO ADDRESS THIS FORUM ON A TOPIC OF SUCH MAJOR IMPORTANCE AS THE EPIDEMIC OF AIDS.

I WANT TO THANK MR. CHEN, YOUR EXECUTIVE DIRECTOR, AND MR. PHILLIP CARRA AND DR. JACK HOPKINS FOR EXTENDING THE INVITATION. AND A SPECIAL WORD OF THANKS TO MY FRIEND AND VALUED COLLEAGUE, DR. TED COOPER.

I'VE TOLD HIM IN PRIVATE BUT I'D LIKE TO SAY IT PUBLICLY AS WELL. I BRING DR. COOPER THE GREETINGS OF HIS MANY FRIENDS IN THE CAREER SERVICE WHO STILL LABOR AT N.I.H. AND ON THE 7<sup>th</sup> Floor OF THE HUBERT HUMPHREY BUILDING, THE HEADQUARTERS FLOOR OF THE U.S. PUBLIC HEALTH SERVICE.

THIS EVENING I WOULD LIKE TO SHARE WITH YOU MY PERCEPTION OF WHAT EFFECT THE EPIDEMIC OF AIDS IS HAVING UPON THE WAY AMERICANS THINK ABOUT DISEASE ... ABOUT HEALTH ... AND ABOUT RESPONSIBILITY, BOTH PERSONAL AND SOCIAL.

MAKE NO MISTAKE ABOUT IT. AIDS IS NOT JUST A DISEASE

AFFECTING THE BODIES AND MINDS OF A FEW THOUSAND PEOPLE. HERE IN

MICHIGAN, CLOSE TO 530 PEOPLE HAVE BEEN REPORTED AS HAVING AIDS,

SINCE THE RECORD-KEEPING BEGAN BACK IN 1981. THAT'S NOT A GREAT

NUMBER, RELATIVE TO THE NATIONAL TOTAL OF ALMOST 53,000.

BUT IF YOU LOOK AT NUMBERS ALONE, YOU'LL MISS THE REAL STORY OF THIS DISEASE, FOR AIDS HAS BURROWED ITS WAY INTO THE FABRIC OF AMERICAN LIFE AND, UNLESS WE RECOGNIZE THE DAMAGE IT COULD DO THERE, WE CAN LOSE MORE THAN HUMAN LIVES. AND BOTH EFFECTS ARE CATASTROPHES, OF COURSE.

HERE IN THE UNITED STATES AS WELL AS IN OVER 100 COUNTRIES AROUND THE WORLD, THE DISEASE OF AIDS THREATENS NOT ONLY THE LIVES OF ORDINARY CITIZENS, BUT ALSO A NATION'S SOCIAL COHESION AND NATIONAL PURPOSE.

OUR JOB -- AS CITIZENS, COMMUNITY LEADERS, AND AS PHYSICIANS
-- MUST BE TWO-FOLD: TO SAVE THOSE INDIVIDUAL HUMAN LIVES ... AND
TO SAVE OUR COUNTRY.

WHY IS THIS THE CASE? WHAT MAKES THIS DISEASE SO THREATENING?

AS A BEGINNING, LET ME BRIEFLY REMIND YOU OF THREE ASPECTS OF THE DISEASE THAT COLOR EVERYTHING DONE AND SAID ABOUT IT.

FIRST, AIDS IS STILL A MYSTERY. WE KNOW SOME THINGS ABOUT IT. BUT WE DON'T KNOW ENOUGH ABOUT IT TO PRODUCE A VACCINE TO PREVENT ITS SPREAD OR A DRUG TO STOP IT IN ITS TRACKS.

TWO, IT'S FATAL. IN FACT, IT SEEMS TO HAVE ONE OF THE HIGHEST FATALITY RATES OF ANY INFECTIOUS DISEASE WE'VE EVER COME ACROSS.

AND THREE, THE AIDS VIRUS IS TRANSMITTED BY CERTAIN
BEHAVIORS THAT MOST PEOPLE DON'T ENGAGE IN OR APPROVE OF: ANAL
INTERCOURSE, FOR EXAMPLE, AND THE SHARING OF NEEDLES BY DRUG
ADDICTS.

THESE THREE KEY ASPECTS OF THE DISEASE MAKE THE AMERICAN PEOPLE VERY EDGY ABOUT AIDS -- AND WHO CAN BLAME THEM?

WE HAVE EVERY REASON TO BE CAUTIOUS. BUT NO REASON TO BECOME PARALYZED. YET, SOME AMONG US ARE INDEED PARALYZED BY IT: SCHOOL OFFICIALS WHO HAVE BARRED CHILDREN WITH AIDS FROM PUBLIC CLASSROOMS, PHYSICIANS AND HOSPITAL ADMINISTRATORS WHO TURN AWAY AIDS PATIENTS, AND EMPLOYERS WHO SUMMARILY DISMISS ANY WORKER WHO HAS AIDS.

JUST THE OTHER DAY I SAW THE RESULTS OF A SURVEY CONDUCTED BY THE CENTER FOR WORK PERFORMANCE PROBLEMS AT GEORGIA TECH:

TWO-THIRDS OF THE WORKERS SURVEYED SAID THEY WOULD BE "CONCERNED" ABOUT SHARING A RESTROOM AT WORK WITH A COLLEAGUE WHO HAD AIDS.

FORTY PERCENT WEREN'T SURE ABOUT THE WISDOM OF EATING IN THE SAME CAFETERIA WITH PERSONS WITH AIDS.

AND 37 PERCENT WOULD NOT SHARE TOOLS OR EQUIPMENT WITH PEOPLE WHO HAD THE AIDS VIRUS.

THESE ARE IRRATIONAL AND DISCRIMINATORY RESPONSES. AND WE NEED TO RECOGNIZE THEM FOR WHAT THEY ARE AND WE MUST CONVINCE OUR COLLEAGUES NOT TO ADOPT THEM.

I SAY THESE RESPONSES ARE IRRATIONAL BECAUSE THEY ARE MADE IN THE NAME OF PROTECTION AGAINST DANGER. BUT IN ALL THOSE SITUATIONS, NEITHER THE DISEASE NOR THE PERSON WHO HAS IT PRESENTS ANY CLEAR OR PRESENT DANGER.

AS I INDICATED EARLIER, A PERSON HAS TO KNOWINGLY DO CERTAIN THINGS TO BECOME INFECTED WITH THE VIRUS. NOW, IF THOSE KINDS OF THINGS ARE GOING ON IN YOUR SCHOOL ... YOUR HOSPITAL ... OR YOUR PLACE OF BUSINESS, BELIEVE ME, AIDS IS THE LEAST OF YOUR PROBLEMS.

AT ANY RATE, TWO YEARS AGO THE PUBLIC HEALTH SERVICE
RELEASED A SET OF PRACTICAL GUIDELINES WHICH, IF FOLLOWED, WILL
PROTECT ANY HEALTH WORKER FROM BECOMING CONTAMINATED OR INFECTED
WITH THE AIDS VIRUS.

AND THEY'RE EFFECTIVE. SO FAR, OUT OF A TOTAL HEALTH WORKFORCE OF NEARLY 7 MILLION PERSONS, FEWER THAN A DOZEN HAVE BECOME INFECTED WITH THE AIDS VIRUS ON THE JOB.

AND IN EACH OF THOSE CASES, I THINK YOU WILL SEE A POINT WHERE VIGILANCE WAS RELAXED AND THE VIRUS FOUND A WAY IN.

DESPITE THIS EXTRAORDINARY RECORD OF SAFETY, WE HEAR ALMOST DAILY SOME STORY INVOLVING A HEALTH PROFESSIONAL -- OR A GROUP OF PROFESSIONALS -- WHO REFUSE TO TREAT SOMEONE WITH AIDS ... OR THEY REFUSE EVEN TO TREAT SOMEONE WHOM THEY SUSPECT OF HAVING AIDS.

I DO NOT FOR A MOMENT BELIEVE THAT THIS IS THE
CHARACTERISTIC BEHAVIOR OF ALL HEALTH PROFESSIONALS. QUITE THE
CONTRARY: THE OVERWHELMING MAJORITY OF MY COLLEAGUES HAVE
PROVIDED -- AND I AM CERTAIN WILL CONTINUE TO PROVIDE -QUALITY, COMPASSIONATE CARE TO PERSONS DYING OF AIDS WHEREVER
THAT MAY BE OCCURRING.

BUT THE <u>GOOD</u> CONDUCT OF THE MAJORITY SHOULD NOT IN ANY WAY SHIELD THE <u>POOR</u> CONDUCT OF A FEARFUL AND IRRATIONAL MINORITY.

I RAISE THIS ISSUE WITH YOU, BECAUSE THIS IS NOT A PROBLEM THAT ONLY GOVERNMENT CAN SOLVE.

FORTUNATELY, THE RESPONSE OF MANY PRIVATE ORGANIZATIONS TO THE DANGER OF IRRATIONAL BEHAVIOR HAS BEEN MOST ENCOURAGING:

- \* THE AMERICAN MANAGEMENT ASSOCIATION HAS DEVELOPED
  BRIEFING MATERIALS ON AIDS WHICH EXPLAINS THE NATURE OF THE
  DISEASE ... HELPS MANAGERS PREPARE AN EDUCATIONAL PROGRAM ON THE
  SUBJECT ... AND OFFERS SOME ADVICE FOR DEALING WITH AN EMPLOYEE
  WITH THE DISEASE IN A HUMANE, DECENT WAY.
- \* THE NATIONAL EDUCATION ASSOCIATION HAS DONE THE SAME FOR ITS MEMBERS, PROVIDING GUIDELINES FOR BOTH THE ADMISSION OF SCHOOL CHILDREN WITH AIDS AND THE HIRING AND SUPERVISION OF EMPLOYEES WITH AIDS.

\* INDIVIDUAL BUSINESSES, SUCH AS AT&T, WESTINGHOUSE, AND THE SAN FRANCISCO-BASED WELLS FARGO AND BANKAMERICA WERE AMONG THE FIRST OF MANY TO DO SOMETHING POSITIVE ABOUT AIDS EDUCATION AND EMPLOYEE POLICIES FOR THEIR OWN COMPANIES.

AS A MATTER OF FACT, THERE IS STILL A GREAT DEAL THAT LOCAL, COMMUNITY LEADERS, SUCH AS YOURSELVES, CAN DO TO MAINTAIN A RATIONAL, COMPASSIONATE APPROACH TO THIS PROBLEM.

AND I DO NOT FOR A MINUTE BELIEVE THAT YOU NEED TO COMPROMISE IN ANY WAY JUST HOW YOU FEEL ABOUT THE KINDS OF BEHAVIOR THAT MAKES AIDS POSSIBLE.

BUT WE MUST KEEP OUR PRIORITIES STRAIGHT. WE ALWAYS HAVE IN THE PAST. WE OUGHT TO DO THE SAME NOW. THE FIRST PRIORITY IS TO FIGHT THE DISEASE AND NOT THE PEOPLE WHO HAVE IT. THE SECOND PRIORITY IS TO EDUCATE EVERYONE ABOUT THE DISEASE SO THAT IT WILL NOT BE SPREAD.

HOW DO YOU ACCOMPLISH PRIORITY ONE? AGAIN, WITH GOOD INFORMATION. YOU NEED TO UNDERSTAND, FOR EXAMPLE, THAT EACH PERSON CAN AVOID THE RISK OF CONTAMINATION OR INFECTION BY USING COMMON SENSE AND FOLLOWING A FEW SIMPLE RULES...

AND YOU NEED TO AGREE THAT NO ONE SHOULD BE ABLE TO USE THE FEAR OF AIDS AS A SHIELD BEHIND WHICH HE OR SHE CAN VIOLATE THE ETHICS OF MEDICINE OR EDUCATION OR SOCIAL SERVICE. NO ONE SHOULD HAVE THE LEEWAY TO ESCAPE THE MORAL IMPERATIVE IN OUR SOCIETY THAT WE MUST SERVE PEOPLE WHO ARE IN NEED.

NOW I WANT TO BRING UP AN OTHER, RELATED ISSUE ... ONE THAT IS EVEN MORE DIFFICULT TO HANDLE. AND THAT'S THE ISSUE OF COSTS ... MORE SPECIFICALLY, THE COST OF CARE FOR AIDS PATIENTS.

THIS IS NOT A THEORETICAL OR ACADEMIC QUESTION AT ALL,

BECAUSE THE COST OF PATIENT CARE IN THIS NEW AND EXPANDING AREA
IS ALREADY HIGH -- AND IT'S GOING TO GET HIGHER.

AT THIS POINT THE TOTAL ANNUAL EXPENDITURE FOR THE MEDICAL CARE OF AIDS PATIENTS IS ABOUT \$1.6 BILLION. HOWEVER, OF THAT TOTAL, THE AMERICAN TAXPAYER CONTRIBUTES ABOUT 1 DOLLAR OF EVERY 4, OR SOMETHING ON THE ORDER OF \$400 MILLION.

WE ANTICIPATE THAT, OVER THE NEXT FOUR YEARS, THE ANNUAL AIDS CASE-LOAD WILL MORE THAN DOUBLE AND THE ANNUAL COST OF CARE WILL MORE THAN TRIPLE.

ORDINARILY WE DON'T WORRY ABOUT THIS. WE'VE HAD A BILLION-DOLLAR PROGRAM TO FIGHT CANCER ... WE'VE PUT HUNDREDS OF MILLIONS OF DOLLARS INTO KIDNEY DIALYSIS ... AND, ON THE WHOLE, THESE KINDS OF EXPENDITURES HAVE BEEN SUPPORTED WITH MUCH GOOD GRACE BY THE AMERICAN TAXPAYER.

MOST OF THOSE BIG- AND SMALL-TICKET PUBLIC HEALTH PROGRAMS, HOWEVER, HAVE HAD A COMMONALITY OF SORTS:

MOST OF THEM EITHER HELP <u>PROMOTE OR MAINTAIN</u> AN INDIVIDUAL'S GOOD HEALTH ... OR THEY HELP AN AILING INDIVIDUAL <u>RETURN</u> TO A STATE OF GOOD HEALTH.

JUST THINK ABOUT IT FOR A MOMENT AND I'M SURE YOU WILL AGREE. THERE'S THE MATERNAL AND CHILD HEALTH PROGRAM ... OUR ALCOHOLISM PROGRAMS ... DRUG ABUSE ... HYPERTENSION SCREENING ... AND SO ON.

BUT THE PROGRAM TO SUPPORT CARE FOR AIDS PATIENTS IS QUITE DIFFERENT. IT'S VERY EXPENSIVE, AS I'VE ALREADY INDICATED. THE ANNUAL COST PER PATIENT IS NOW RUNNING BETWEEN \$20,000 AND \$50,000, DEPENDING ON THE CITY AND THE TYPE OF AIDS-RELATED CONDITION THE PERSON HAS.

BUT THEN, AFTER CONSUMING TENS OF THOUSANDS OF DOLLARS
WORTH OF MEDICAL CARE AND SOCIAL SERVICES ... THE AIDS PATIENT
DIES. WE KNOW IT'S GOING TO HAPPEN. SOME OF THE COST IS SPENT
ON HOSPICE CARE AS IT IS.

THIS IS A TERRIBLY IMPORTANT ISSUE FOR THIS COUNTRY. WE HAVE A TRULY ENVIABLE TRADITION OF ALTRUISM IN AMERICA ... A KIND OF NATIONAL ETHOS OF BENEVOLENCE ... AND IT'S A PRECIOUS TRADITION.

AIDS HAS THE POTENTIAL OF PUTTING THAT TRADITION AT RISK.

IT IS A VIRTUALLY FATAL DISEASE THAT A PERSON CONTRACTS BY

INDULGING IN BEHAVIOR THAT MOST AMERICANS WILL NOT CONDONE. YOU

CAN SAY THE SAME THING FOR ALCOHOLISM, DRUG ABUSE, RECKLESS

DRIVING, VENEREAL DISEASE, AND TEENAGE PREGNANCY.

BUT AIDS PROVOKES A QUITE DIFFERENT RESPSONSE, I CAN TELL
YOU FROM MY OWN PERSONAL EXPERIENCES DURING THE EIGHT MONTHS I
TOOK TO PREPARE THE "SURGEON GENERAL'S REPORT ON AIDS." MOST
PEOPLE CAME TO ME AND OFFERED THEIR ADVICE, BUT IT TENDED TO BE
WITHIN THE GENERAL FRAMEWORK OF OUR TRADITION OF TOLERANCE ALMOST
TO A FAULT.

BUT OTHERS WERE NOT SO GENEROUS. AND I HEAR ECHOES OF THEIR IRRATIONAL AND EVEN HATEFUL RESPONSE TO AIDS AND THE PEOPLE WITH AIDS, AS A I MENTIONED A FEW MOMENTS.

WILL THE AMERICAN PEOPLE CONTINUE TO SUPPORT HIGH-COST

PATIENT CARE FOR PEOPLE WITH AIDS? OR WILL THEY ASK FOR RELIEF?

AND IF THEY DO SEEK RELIEF -- WHICH WILL BE NEW FOR OUR SOCIETY -- WHAT AFFECT WILL THAT HAVE ON ACCESSIBILITY TO MEDICAL CARE...OR ON THE QUALITY OF CARE...FOR AIDS PATIENTS?

MY GUESS IS THAT THE EFFECT WILL NOT BE GOOD FOR AIDS

PATIENTS IN THE SHORT RUN AND NOT GOOD FOR OUR COUNTRY IN THE

LOMNG RUN.

I'D LIKE TO THINK THAT THE AMERICAN TAXPAYER WILL DO THE RIGHT THING AND CONTINUE TO SUPPORT QUALITY, ACCESSIBLE CARE FOR ALL AIDS PATIENTS. BUT I'M UNEASY ENOUGH TO CONFESS TO YOU RIGHT NOW THAT -- HONESTLY -- I JUST DON'T KNOW.

AS A PHYSICIAN, I AM PROUD TO BE PART OF A TRADITION OF CARE THAT GOES BACK MORE THAN TWO MILLENIA...A TRADITION THAT WILL NOT ABANDON THE SICK AND THE DISABLED, WHOEVER THEY ARE AND WHATEVER THEY MAY HAVE DONE TO HAVE ARRIVED IN SUCH A FIX.

FINALLY, WE SEE MORE EVIDENCE EVERY DAY THAT THIS DISEASE IS BECOMING THE PARTICULAR SCOURGE OF PEOPLE WHO ARE YOUNG, BLACK, AND HISPANIC. AMONG PERSONS WITH AIDS WHO ARE UNDER 30 YEARS OF AGE, 25 PERCENT ARE BLACK AND 14 PERCENT ARE HISPANIC.

THESE PERCENTAGES ARE <u>TWICE</u> THE RATES AT WHICH THESE GROUPS APPEAR IN THE POPULATION AS A WHOLE.

AMONG WOMEN IT'S EVEN WORSE: 52 PERCENT OF ALL WOMEN WITH AIDS ARE BLACK ... 20 PERCENT ARE HISPANIC.

HOW TRAGIC FOR THEM.

AND HOW TRAGIC FOR ALL OF US.

ANYONE WHO HAS LIVED THROUGH THE LAST TWO DECADES OF SOCIAL CHANGE IN THIS COUNTRY HAS GOT TO BE PROUD OF THE WAY THIS COUNTRY HAS FACED THE CHALLENGE OF FAIRNESS TO ALL ITS CITIZENS, REGARDLESS OF RACE, COLOR, CREED, AGE, SEX, OR NATIONAL ORIGIN.

IT HASN'T BEEN EASY AND IT HASN'T BEEN PERFECT. BUT GRAEAT STRIDES HAVE BEEN MADE.

WILL THE DISEASE OF AIDS -- ALL BY ITSELF -- REVERSE THIS

TREND IN RECENT HUMAN HISTORY? WILL THIS DISEASE -- BY ITSELF -
RAISE ONCE AGAIN THE ARTIFICIAL BARRIERS BETWEEN OUR CITIZENS

THAT IT TOOK SO MUCH WORK AND COURAGE TO TEAR DOWN?

WE HOPE AND PRAY THAT IT WILL NOT. BUT HOPES AND PRAYERS MAY NOT BE ENOUGH. WE WILL NEED TO REINFORCE THOSE HOPES AND PRAYERS WITH THE HELP OF COURAGEOUS LEADERSHIP AT ALL LEVELS OF GOVERNMENT AND THROUGHOUT ALL OUR SOCIAL AND POLITICAL INSTITUTIONS.

YES, IT IS TRUE THAT THE GREAT MAJORITTY OF AIDS PATIENTS SO FAR HAVE BEEN HOMOSEXUALS, DRUG ADDICTS, BLACKS, AND HISPANICS.
ABOUT 47,000 OF THEM.

AND SO WE MUST ASK IF WE ARE TRULY MATURE ENOUGH TO BE COLOR-BLIND IN THIS WAR AGAINST AIDS?

CAN WE BE "VIROPHOBIC" WITHOUT BEING HOMOPHOBIC?

ARE WE SECURE ENOUGH TO STRIVE TO EXTEND OUR <u>VERY BEST</u>
MEDICAL CARE TO THE <u>EVERY</u> CITIZEN WHO NEEDS IT?

THESE AND OTHER QUESTIONS LIE ON THE HORIZON BEFORE US. BUT THE HORIZON IS NOT THAT FAR AWAY. I HOPE WE WILL NOT STUMBLE TOWARD IT AND ARRIVE UNPREPARED FOR THE CHALLENGES THAT LIE BEYOND.

I HOPE THAT, INSTEAD, WE WILL MOVE FORWARD WITH GOOD SENSE AND GOOD SCIENCE AND, TOGETHER, GIVE THE WORLD SOMETHING EVERY BIT AS PRECIOUS AS THE MUCH-DESIRED AIDS VACCINE: WE WILL SHOW THE WORLD HOW COMPASSION AND JUSTICE CAN TRIUMPH OVER DISEASE.

ONCE AGAIN...THANK YOU.

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