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A MOMENT OF OPPORTUNITY

BY

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KEYNOTE ADDRESS TO THE FIRST MEETING OF THE
SOCIETY OF HANDICAPPED PHYSICIANS
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(GREETINGS TO HOSTS, GUESTS, ETC.)

IT IS ALWAYS AN HONOR TO BE INVITED TO DELIVER THE KEYNOTE ADDRESS FOR ONE MEETING OR ANOTHER. BUT THIS AFTERNOON, I FEEL ESPECIALLY PRIVILEGED TO SPEAK WITH A GROUP OF PHYSICIANS WHO NOT ONLY HAVE PARTICULAR PERSONAL AND PROFESSIONAL NEEDS BUT ALSO HAVE SPECIFIC SKILLS AND PERCEPTIONS TO OFFER THE AMERICAN PEOPLE.

AS MANY OF YOU KNOW THROUGH FIRST-HAND EXPERIENCE, DR. SPENCER B. LEWIS WAS THAT KIND OF PHYSICIAN -- TRUE TO HIS PROFESSION, TO HIMSELF, TO HIS FAMILY, AND TO THE PEOPLE HE SERVED. HIS SUDDEN DEATH LAST APRIL WAS A SEVERE BLOW TO US ALL. HIS WIDOW, MRS. MARY LEWIS, CALLED HER LATE HUSBAND "A MAN OF COURAGE AND GREAT DETERMINATION AND COMPASSION." THOSE QUALITIES ARE ALWAYS IN SHORT SUPPLY. AND SO WE MOURN THE LOSS OF ANY PERSON WHO HAS DEMONSTRATED THEM IN THE WAY DR. LEWIS DID WHEN HE WAS ALIVE AND PRACTICING MEDICINE. THIS YEAR WILL BE REMEMBERED AS THE LAST ONE IN WHICH OUR SOCIETY WAS ENRICHED BY THE PRESENCE OF DR. SPENCER B. LEWIS.

COINCIDENTALLY, 1982 HAS BEEN PROCLAIMED BY PRESIDENT REAGAN AS THE "NATIONAL YEAR OF DISABLED PERSONS." IT IS OUR FOLLOW-UP OF THE "<u>INTERNATIONAL</u> YEAR OF DISABLED PERSONS," SPONSORED THROUGHOUT 1981 BY THE 158-MEMBER WORLD HEALTH ORGANIZATION. DURING THE CURRENT TWELVE MONTHS, OUR COUNTRY WILL EXAMINE ITS RECORD OF CARE SO FAR AND TRY TO MAKE THE NECESSARY ADJUSTMENTS AND IMPROVEMENTS. FOR THIS, AS WELL AS FOR OTHER MORE PRESSING REASONS, I BELIEVE YOUR MEETING HERE TODAY AND TOMORROW IS PARTICULARLY APPROPRIATE AND TIMELY.

LET ME BEGIN MY REMARKS THIS AFTERNOON WITH A DISCLAIMER: I DO NOT SPEAK AS A PHYSICIAN WHO HAS HIMSELF EXPERIENCED ANY PHYSICAL DISABILITY. RATHER, I AM HERE AS A SURGEON WHO HAS SPENT NEARLY ALL HIS PROFESSIONAL LIFE DEALING WITH THE INTRICATE DISABILITIES OF THE NEWBORN AND THE PROFOUND EFFECTS FELT BY THEIR PARENTS AND FAMILIES. BUT I'VE ALSO WATCHED MANY OF MY FORMER PATIENTS GROW FROM INFANCY INTO ADULTHOOD. SOME ARE NOW IN THEIR LATE 30s AND EARLY 40s. IT HAS GIVEN ME THE UNIQUE CHANCE TO OBSERVE THE LONGITUDINAL DEVELOPMENT OF PERSONS WITH MILD TO SEVERE DISABILITIES.

IN MY PRESENT POSITION AS SURGEON GENERAL, HOWEVER, I HAVE THE CHANCE TO DIRECT ATTENTION TO DISABLED PERSONS EVERYWHERE, REGARDLESS OF THEIR AGE OR OCCUPATION OR STATUS. IT IS MY FERVENT HOPE THAT,

THROUGH ME, THE FEDERAL GOVERNMENT AND THE MEDICAL PROFESSION ITSELF MAY BECOME MORE SENSITIZED TO THE ISSUES RAISED BY ADVOCATES FOR THE DISABLED AND THAT WE WILL NOT ONLY TALK ABOUT THEM...BUT DO SOMETHING FOR THEM.

THIS IS AN ISSUE GROWING IN IMPORTANCE EVERY DAY. AND IT IS PECULIARLY MEDICINE'S ISSUE, SINCE MANY OF OUR PROBLEMS -- AS WELL AS OUR OPPORTUNITIES -- SPRING FROM THE VICTORIES OF CONTEMPORARY MEDICINE AND THE BIOMEDICAL SCIENCES. LET ME ILLUSTRATE THIS WITH A BRIEF LOOK AT SOME RECENT HISTORY.

DURING THE DECADE FROM 1969 THROUGH 1980, THE UNITED STATES EXPERIENCED A DECLINE IN THE MORTALITY RATES ASSOCIATED WITH CERTAIN LEADING DISABLING DISEASES AND TRAUMA. FOR EXAMPLE, THE DEATH RATE FOR HEART DISEASE DROPPED NEARLY 20 PERCENT...FOR STROKE, ABOUT 30 PERCENT...AND FOR ACCIDENTS, THERE WAS A DROP OF 18 PERCENT. I THINK THESE STATISTICS INDICATE THE KIND OF PROGRESS WE HAVE BEEN MAKING IN THE DEVELOPMENT OF EMERGENCY MEDICAL SERVICES AND SYSTEMS, IN THE WIDESPREAD USE OF INTENSIVE CARE TECHNOLOGIES, AND IN THE APPEARANCE OF NEW LIFE-SAVING DRUG THERAPIES AND SURGICAL PROCEDURES DURING THIS PERIOD OF TIME.

MANY OF THE NEW SURVIVORS OF THE PAST DECADE NOW SHOW UP IN ANOTHER CATEGORY: THEY ARE PERSONS WHO ARE LIMITED -- BY ONE OR ANOTHER CHRONIC CONDITION -- FROM CARRYING OUT ACTIVITIES NORMAL FOR PEOPLE THEIR AGE OR SEX. THEY INCLUDE THE...

16.5 MILLION MEN AND WOMEN WHO SUFFER FROM A CHRONIC HEART CONDITION,

THE 9.9 MILLION SUFFERING FROM HYPERTENSION,

THE 4.5 MILLION WHO ARE VISUALLY IMPAIRED -- PARTIALLY OR TOTALLY BLIND,

THE 2.4 MILLION WHO HAVE A HEARING IMPAIRMENT -- PARTIALLY OR TOTALLY DEAF,

AND THE 5.4 MILLION WITH IMPAIRMENTS OF THE BACK, SPINE, HIPS, ARMS, AND LEGS.

IN 1969 APPROXIMATELY 23 MILLION AMERICANS WERE LIMITED BY ONE OR MORE CHRONIC CONDITIONS. HOWEVER, BY 1980 MORE THAN 31 MILLION AMERICANS WERE IN THIS CATEGORY. THE PERCENTAGE OF THE POPULATION THEY REPRESENTED ALSO CREPT UP FROM 11.6 PERCENT IN 1969 TO 14.4 PERCENT IN 1980.

IN OTHER WORDS, ABOUT 1 IN EVERY 7 AMERICANS IS DISABLED AS A RESULT OF A CHRONIC CONDITION -- OR OF SEVERAL CONDITIONS AT ONCE -- AND MUST LIMIT HIS OR HER WAY OF LIFE...LIVING A LIFE THAT IS DIFFERENT FROM THAT OF PERSONS THE SAME AGE AND SEX.

BUT EVEN HERE WE ENCOUNTER SOME TROUBLE. WE STILL HAVE NOT AGREED ON WHAT A "DISABILITY" OR A "HANDICAP" REALLY IS IN PRECISE LEGAL OR MEDICAL TERMS. THIS POINT WAS RECENTLY MADE IN A REPORT TITLED <u>HEALTH CARE IN A CONTEXT OF CIVIL RIGHTS</u>, PRODUCED BY THE INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMY OF SCIENCES. THE REPORT OBSERVES THAT THE GOVERNMENT HAS USED 16 DIFFERENT MEANINGS FOR "HANDICAPPED" OR "DISABLED" IN THE COURSE OF CARRYING OUT 66 DIFFERENT FEDERAL PROGRAMS.

THE REPORT BY THE INSTITUTE OF MEDICINE ALSO MAKES THE FOLLOWING IMPORTANT OBSERVATION:

> "THE NEEDS OF HANDICAPPED PERSONS FREQUENTLY ARE FOR SERVICES NOT PROPERLY CALLED 'MEDICAL,' BUT RATHER ARE SOCIAL, PSYCHOLOGICAL, AND/OR REHABILITATIVE. THUS, THE QUESTION OF ADEQUACY OF SERVICES FOR HANDICAPPED PERSONS IS NOT ONLY A QUESTION OF WHETHER THEY RECEIVE THE NEEDED <u>AMOUNT</u> OF MEDICAL SERVICES BUT ALSO WHETHER THEY RECEIVE THE APPROPRIATE <u>TYPE</u> OF SERVICES."

THE REPORT WAS PREPARED BY A SPECIAL COMMITTEE TO STUDY THE PATTERNS OF HEALTH CARE SERVING RACIAL AND ETHNIC MINORITIES AND HANDICAPPED PERSONS. CHAIRING THIS INSTITUTE OF MEDICINE COMMITTEE WAS A FORMER COLLEAGUE OF MINE, DR. ROSEMARY STEVENS, PROFESSOR OF HISTORY AND THE SOCIOLOGY OF SCIENCE AT THE UNIVERSITY OF PENNSYLVANIA. SHE AND THE MEMBERS OF THAT PRESTIGIOUS COMMITTEE REPRESENT MANY THOUSANDS OF PROFESSIONALS WHO REMAIN CONCERNED ABOUT EQUITY AND FAIRNESS IN AMERICAN HEALTH CARE.

AS A NATION, WE NEED THIS KIND OF IN-DEPTH UNDERSTANDING. THE UNITED STATES, AFTER ALL, IS ONLY JUST BEGINNING TO GRAPPLE WITH THE MORAL, ETHICAL, AND FISCAL ISSUES SURROUNDING THE LIVES OF ITS DISABLED CITIZENS. I WOULD HOPE THAT YOU, AS MEMBERS OF THIS NEW SOCIETY OF HANDICAPPED PHYSICIANS, WOULD ALSO BEGIN TO LOOK AT THESE ISSUES. THE PRACTICE OF MEDICINE IN TODAY'S WORLD CAN BENEFIT FROM EYESIGHT... BUT IT WILL BENEFIT EVEN MORE FROM _YOUR_ _IN_SIGHT.

THERE ARE ANY NUMBER OF QUESTIONS THAT CRY OUT FOR ANSWERS. BUT, AT THIS TIME, LET ME SHARE WITH YOU SOME QUESTIONS THAT WE, AS PHYSICIANS AND AS AMERICANS, MUST ADDRESS RIGHT NOW. I LIST THEM IN NO SPECIAL RANK ORDER; TO ME, THEY ARE _ALL_ VERY IMPORTANT.

FIRST, WE NEED TO REVISE MANY OF OUR RESEARCH AND SERVICE STRATEGIES. THEY HAVE USUALLY BEEN STRUCTURED ON A DISEASE-BY-DISEASE OR DISABILITY-BY-DISABILITY BASIS. BUT, ACCORDING TO SOME ESTIMATES, AS MANY AS A THIRD OF OUR DISABLED MAY SUFFER FROM _MULTIPLE_ CHRONIC CONDITIONS. SOME JUDGMENTS HAVE TO BE MADE AS TO THE LEVEL OF EFFORT TO BE EXPENDED ON ONE OR ANOTHER CONDITION, RELATIVE TO ITS EFFECT ON AN INDIVIDUAL WITH ONE OR MORE OTHER CONDITIONS.

THIS WON'T BE EASY, SINCE WE ARE CONDITIONED TO COME AS CLOSE AS WE CAN TO PUTTING FORTH A 100 PERCENT EFFORT -- INCLUDING FUNDS -- IN ORDER TO OVERCOME EACH DISABILITY. TODAY THAT'S NOT ONLY IMPOSSIBLE, IT'S NO LONGER EVEN USEFUL AS A REALISTIC RESEARCH AND SERVICE STRATEGY.

<u>SECOND</u>, WE'VE GOT TO CLARIFY JUST <u>WHO</u> IT IS WHO PAYS <u>WHAT</u> COSTS FOR CHRONIC ILLNESS AND DISABILITY. THUS FAR, WE HAVE BEEN WILLING TO LET MOST OF THE FINANCIAL BURDEN FALL UPON DISABLED PERSONS THEMSELVES AND THEIR FAMILIES. IN ADDITION, I SUSPECT THAT SOCIETY'S RELATIVELY SMALL CONTRIBUTION VERY LIKELY HAS ITS ROOTS IN THE HISTORIC NOTION THAT SUCH PAYMENT IS A COMPENSATION FOR THE DISABLING CONDITION. THERE'S A LITTLE HINT OF GUILT IN MANY PROGRAMS OF PUBLIC SUPPORT. AND I SUPPOSE THAT'S ONLY HUMAN NATURE. BUT UNFORTUNATELY IT <u>DOES</u> TEND TO PLACE SOCIETY'S FOCUS ALMOST ENTIRELY UPON THE <u>CONDITION</u> -- HOW MUCH IS IT WORTH? -- AND ONLY INCIDENTALLY UPON THE <u>PERSON</u> WHO <u>HAS</u> THE CONDITION.

I BELIEVE THAT SUCH A FOCUS IS NOT USEFUL IN OUR KIND OF SOCIETY. WE SET GREAT STORE BY THE PARTICIPATION OF ALL MEMBERS OF SOCIETY IN OUR POLITICAL, SOCIAL, AND ECONOMIC PROCESSES. OUR NATION HAS DRAWN ITS STRENGTH FROM THIS VERY IDEA THAT THE COUNTRY BELONGS TO EVERYONE -- AND, THEREFORE, THE CONDUCT OF ITS BUSINESS IS EVERYONE'S RESPONSIBILITY.

BUT THAT WILL CONTINUE TO BE ONLY RHETORIC, IF WE FORGET THAT SOME PERSONS JUST DON'T HAVE THE MATERIAL WHEREWITHAL TO PARTICIPATE IN THE FULL LIFE OF THE NATION. THEREFORE, I BELIEVE THAT THE AMERICAN DOCTRINE OF "FAIRNESS" DICTATES THAT WE OUGHT TO DO MORE TO CONTRIBUTE TO A PERSON'S CAPACITY FOR PARTICIPATION IN OUR SOCIETY, AND THAT WE SHOULD PUT INTO A MORE BALANCED PERSPECTIVE THE WAY WE COMPENSATE A PERSON FOR ENDURING A SPECIFIC CONDITION OR DISABILITY.

PHRASED ANOTHER WAY, OUR QUESTIONS MIGHT BE:

> "DO WE CONTINUE TO HELP SUPPORT SOMEONE BECAUSE HE OR SHE IS A PARAPLEGIC...OR BECAUSE THE SUPPORT IS NEEDED TO GET THAT PARAPLEGIC TO AND FROM WORK?"
>
> "DO WE PROVIDE A DISABILITY PAYMENT TO A HANDICAPPED PHYSICIAN, FOR EXAMPLE, BUT PREVENT THAT PHYSICIAN FROM OBTAINING A LICENSE RENEWAL, HOSPITAL PRIVILEGES, OR PATIENT REFERRALS?"

I THINK WE HAVE TO FACE SUCH QUESTIONS AND GIVE THEM FRESH, NEW ANSWERS.

THIRD, AND RELATED TO THE "FAIRNESS" ISSUE I JUST RAISED, IS THE WHOLE RE-EVALUATION NOW GOING ON CONCERNING THE ROLE OF INSTITUTIONS OF CARE AND OF THE ALTERNATIVES TO INSTITUTIONALIZATION.

THERE'S NO QUESTION BUT THAT THE PENDULUM IS SWINGING THE OTHER WAY, AGAINST INSTITUTIONALIZATION AND IN FAVOR OF THE RE-ABSORPTION OF DISABLED PERSONS BY FAMILY AND COMMUNITY. AND THAT IS CERTAINLY THE IDEAL WAY TO MOVE, TO MY WAY OF THINKING. BUT THE WALLS OUTSIDE AN INSTITUTION MAY BE JUST AS HIGH AND AS IMPENETRABLE AS THE WALLS INSIDE AN INSTITUTION. PUBLIC FACILITIES MAY HAVE NEEDLESS BARRIERS, OCCUPATIONS MAY HAVE OUTMODED REQUIREMENTS, AND IGNORANCE AND PREJUDICE MAY STILL BE ACCEPTED BEHAVIOR AMONG TOO MANY SO-CALLED ABLE-BODIED OR SIGHTED PERSONS.

I'M THINKING NOW ESPECIALLY OF OUR ELDERLY CITIZENS. NOT LONG AGO I WAS DISCUSSING THEIR PROBLEMS WITH A VERY PERCEPTIVE SOCIAL SERVICE WORKER WHO DESCRIBED THE PLIGHT OF MANY ELDERLY HOMEMAKERS, NOW IN

THEIR LATE 60s OR 70s, WHO MAY HAVE A BRIEF PERIOD OF IN-PATIENT CARE AND THEN ARE SENT BACK TO THEIR NEIGHBORHOODS AND THEIR HOMES. WHEN THEY RETURN HOME, THEY ACTUALLY MAY BE LESS CAPABLE OF INDEPENDENT LIVING, YET THEY MAY NO LONGER HAVE THE HUMAN RESOURCES TO SUPPLY THE HELP THEY NEED IN THEIR TINY APARTMENTS OR OUT AMONG THEIR NEIGHBORS.

THERE IS ALSO THE PHENOMENON OF THE AGED PARENT WHO HAS OUTLIVED HIS OR HER CHILDREN, WHO HAS SURVIVED STROKE AND HEART DISEASE THROUGH THE MIRACLE OF MODERN MEDICINE, BUT WHO CANNOT SURVIVE THE ORDINARY STRESSES OF LIVING IN AN EMPTY HOME -- EMPTY OF HELP AND EMPTY OF HOPE.

THIS IS ANOTHER PROBLEM THAT WILL NOT GO AWAY. IN FACT, THERE IS EVERY INDICATION IT WILL BECOME AGGRAVATED AS THE AMERICAN SENIOR CITIZEN POPULATION BEGINS TO EXPAND DRAMATICALLY OVER THE NEXT THREE DECADES. THIS GROUP WILL INCLUDE NOT ONLY THOSE PERSONS WHO WERE DISABLED IN THEIR MIDDLE ADULT YEARS, BUT ALSO THOSE PERSONS NEW TO THE WORLD OF DISABILITY WHO CANNOT COPE VERY WELL WITH DAILY PROBLEMS OF A HANDICAPPED LIFE.

FOR A FEW, THE ANSWER MAY STILL BE THE PROTECTION AND THE SERVICE OF AN INSTITUTION. BUT FOR MOST OTHERS, THE ANSWER OUGHT TO BE A HIGHER LEVEL OF CARE AND INTEREST BY RESPONSIVE FAMILIES AND COMMUNITIES. BOTH ANSWERS, HOWEVER, NEED TO BE UNDERSTOOD AND NURTURED BY OUR SOCIETY.

I CAN TELL YOU THAT THIS ISSUE IS OF MAJOR CONCERN TO MANY OTHER SOCIETIES AS WELL. I JUST RETURNED FROM THE WORLD ASSEMBLY ON AGING, HELD IN VIENNA, WHERE OUR UNITED STATES DELEGATION JOINED 110 OTHERS IN DELIBERATING THE MERITS OF INSTITUTIONAL CARE FOR THE ELDERLY. ON ONE POINT WE ALL AGREED, AND THAT IS...WE CAN'T AFFORD TO LEAVE THE MATTER TO CHANCE BECAUSE EXPERIENCE TELLS US THAT THE CONSEQUENCES FOR THE ELDERLY CAN BE SEVERE. IT IS NOT A MATTER TO BE DECIDED BY DEFAULT.

MY <u>FOURTH</u> AND FINAL QUESTION BRINGS US BACK TO A POINT I MADE EARLIER. SOCIETY AS A WHOLE IS NOT LIKELY TO MAKE VERY MUCH PROGRESS TOWARD ANSWERING THE QUESTIONS I'VE RAISED TODAY, UNLESS THE DISABLED COMMUNITY ITSELF PARTICIPATES FULLY IN THE DECISION-MAKING PROCESSES. IT MUST BECOME MORE DEEPLY INVOLVED IN THE DEVELOPMENT OF PUBLIC POLICY AND IN THE FULFILLMENT OF PUBLIC PROMISES. AND WHO BETTER THAN DISABLED PHYSICIANS, WITH THEIR DOUBLE KNOWLEDGE OF <u>CAUSE</u> AND <u>EFFECT</u>, CAN PROVIDE THAT VERY NECESSARY LEADERSHIP?

DISABLED PERSONS HAVE HAD POWERFUL ADVOCATES IN THE PAST AND CERTAIN GROUPS CONTINUE TO MAINTAIN HIGH VISIBILITY AND INFLUENCE. MY FOURTH POINT, THEREFORE, SHOULD NOT BE INTERPRETED AS A CRITICISM. RATHER, IT IS A PLEA THAT YOU PURSUE YOUR GOALS AND MAKE ADJUSTMENTS ALONG THE WAY, ACCORDING TO VICTORIES AND SETBACKS AS THEY APPEAR.

DISABLED PHYSICIANS AND OTHERS WITH LIMITING CONDITIONS WHO PROVIDE HEALTH CARE DO FACE A DOUBLE CHALLENGE: FIRST, YOU HAVE ALL THE HANDICAPS INDISCRIMINATELY PLACED UPON YOU BY THE ABLE-BODIED MAJORITY. SECOND, YOU HAVE THE HANDICAPS IMPOSED BY YOUR ABLE-BODIED COLLEAGUES IN MEDICINE AND BY YOUR POTENTIAL PATIENTS. IT'S A "DOUBLE WHAMMY," AS L'IL ABNER USED TO SAY.

BUT THE BEST POSSIBLE RESPONSE IS THE ONE MADE BY THE DISABLED PHYSICIAN. IT HAS THE RING OF CANDOR AND AUTHORITY. AND IT REPRESENTS <u>YOUR</u> CHARACTER AND <u>YOUR</u> STRENGTH AS HEALTH PROFESSIONALS. FOR THESE REASONS I FULLY SUPPORT THE NEW SOCIETY OF HANDICAPPED PHYSICIANS. I THINK IT COMES AT A SPECIAL MOMENT OF GREAT OPPORTUNITY. I WISH THE ORGANIZATION A LONG AND SUCCESSFUL LIFE WITHIN THE FAMILY OF PROFESSIONAL MEDICAL SOCIETIES. AND I HOPE EACH OF YOU WILL EXERCISE MAXIMUM PARTICIPATION IN THE LIFE OF AMERICAN MEDICINE IN PARTICULAR -- AND IN AMERICAN SOCIETY IN GENERAL.

THANK YOU.

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