19/6

REMARKS

BY

C. EVERETT KOOP, M.D.

SURGEON GENERAL

U. S. PUBLIC HEALTH SERVICE

DEPARTMENT OF HEALTH AND HUMAN SERVICES

PRESENTED TO

SURGEON GENERAL'S CONFERENCE

ON

TRANSITION OF HANDICAPPED CHILDREN TO ADULT CARE

JEKYLL ISLAND, GEORGIA

MARCH 14, 1989

AS I END MY CARRER AS SURGEON GENERAL AND LOOK BACK ON MY ACCOMPLISHMENTS, I SHARE WITH YOU AN ENORMOUS SENSE OF SATISFACTION IN WHAT WE HAVE ACHIEVED FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES.

WE HAVE ESTABLISHED A NATIONAL AGENDA FOR THESE CHILDREN AND THEIR FAMILIES WHICH IS TO:

- PLEDGE A NATIONAL COMMITMENT TO ALL CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES.

- ENCOURAGE BUILDING COMMUNITY-BASED SERVICE SYSTEMS.

- ASSIST IN ENSURING ADEQUATE PREPARATION OF THE PROFESSIONALS WHO PROVIDE CARE.

- DEVELOP COALITIONS TO IMPROVE THE DELIVERY OF SERVICES.

- ESTABLISH GUIDELINES TO CONTROL COSTS OF SERVICES.

- ENCOURAGE AND SUPPORT THE DEVELOPMENT OF ADEQUATE HEALTH CARE FINANCING.

- CONTINUE TO CONDUCT RESEARCH AND DISSEMINATE INFORMATION.

THIS AGENDA IS MOVING FORWARD AS EVIDENCED BY THE MORE THAN 1,200 PARTICIPANTS FROM MEDICINE, HEALTH, EDUCATION, SOCIAL SERVICE FIELDS, AND FAMILIES WHO JOINED US AT THE SEPTEMBER 1988 SURGEON GENERAL'S CONFERENCE IN WASHINGTON.

BEFORE I LEAVE MY POSITION, I WOULD LIKE TO RECALL ONE MAJOR ISSUE IN THE CARE OF SPECIAL CHILDREN WHICH HAS NOT BEEN ADEQUATELY ADDRESSED AND WHICH IS A SIGNIFICANT BARRIER TO OUR ADOLESCENT AND YOUNG ADULT POPULATION AS THEY PURSUE INDEPENDENCE. THAT IS THE BARRIERS THEY ENCOUNTER AND MUST SURMOUNT IF THEY ARE TO SECURE ONGOING QUALITY MEDICAL CARE AS THEY MAKE THAT TRANSITION FROM CHILDHOOD TO ADULTHOOD.

I HAVE INVITED YOU AS LEADERS IN THE MAJOR ORGANIZATIONS AND PROFESSIONS WHICH PROVIDE THESE SERVICES TO HELP US SOLVE THAT PROBLEM.

THIS SURGEON GENERAL'S WORKSHOP, WHICH WILL PROBABLY BE MY LAST, IS SORT OF A PERSONAL EFFORT TO CLOSE THE LOOP ON THE CONFERENCE SOME OF US HAD IN JUNE 1984 AT WAYZATA, MINNESOTA -- A "CONFERENCE ON YOUTH WITH DISABILITIES: THE TRANSITION YEARS". THERE, I WAS A SPEAKER WHO ASKED "WHO ARE THE DISABLED AMONG US." I LEFT THE QUESTION UNANSWERED BUT IMPLIED THAT SOME MEMBERS OF SOCIETY WERE MORE HANDICAPPED THAN THOSE WE CALL DISABLED -- HANDICAPPED BY ATTITUDE, PREJUDICE AND TUNNEL VISION.

TODAY, I AM YOUR KEY NOTE SPEAKER AND IN A SENSE, YOUR HOST.

BECAUSE WE BELIEVED IT NECESSARY AND POTENTIALLY PROFITABLE TO HOLD SUCH A WORKSHOP DOES NOT MEAN THAT ONLY A VACUUM EXISTS ON THE TRANSITION OF DISABLED YOUNGSTERS FROM PEDIATRIC CARE TO THE CARE OF THOSE IN ADULT MEDICINE AND ASSOCIATED SPECIALTIES.

WHAT'S GOOD OUT THERE? LOTS!

- THERE ARE PROGRAMS THAT WORK AND ABOUT THEM YOU WILL HEAR MORE.

- THE ISSUE OF TRANSITION IS BEING ADDRESSED BY A NUMBER OF REGIONAL AND NATIONAL PROGRAMS, MODELS, AND NETWORKING SERVICES WHICH WILL TEACH US HOW BETTER TO PERMIT ADOLESCENTS TO DEVELOP THEIR FULL POTENTIAL BY PARTICIPATING IN COMMUNITY LIFE AS THEY DEVELOP AND GROW WHILE THEY LEARN AND WORK.

- THERE ARE SOCIETIES AND ASSOCIATIONS THAT FOSTER THE EXCHANGE OF INFORMATION AMONG THOSE OF LIKE MIND, SUCH AS THE SOCIETY FOR ADOLESCENT MEDICINE.

- THERE ARE SOME STATES THAT ARE COORDINATORS FOR STATE ADOLESCENT HEALTH PROGRAMS.

- AND SOME STATES HAVE TRAINING AND EMPLOYMENT MODELS.

SPEAKING OF STATES, I HAVE TO GET SOMETHING OFF MY CHEST. YEARS AGO ASTHO -- THE ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS -- HAD A CORDIAL RELATIONSHIP WITH THE SURGEON GENERAL AND ACTUALLY HAD -- I BELIEVE -- AN ANNUAL MEETING -- AT TIMES CALLED THE SURGEON GENERAL'S CONFERENCE -- WHERE NATIONAL AND STATE HEALTH CONCERNS COULD BE EXPOSED, SHARED, AND ADDRESSED.

WHEN I CAME TO WASHINGTON EIGHT YEARS AGO, ASHTO CHOSE TO BELIEVE WHAT THEY READ IN THE PAPERS AND IGNORED ME.

THIS YEAR THEY INVITED ME TO THEIR MEETING NEXT MONTH. BUT IT MUST HAVE BEEN A RATHER HALF-HEARTED INVITATION BECAUSE THEY COULD NOT FIND THE MONEY FOR MY AIR FARE NOR THE WILL TO MEET ME AT THE AIRPORT. SO I'M NOT GOING.

I HOPE THE <u>LEADERSHIP</u> OF ASTHO -- BECAUSE I HAVE CORDIAL AND PROFITABLE RELATIONSHIPS WITH MANY INDIVIDUAL STATE HEALTH OFFICERS -- WILL TRY HARDER WITH MY SUCCESSOR. IT IS A RELATIONSHIP WITH GREAT POTENTIAL FOR SOME OF OUR INTERESTS.

WELL, THEN WHAT'S WRONG WITH AVAILABLE TRANSITION SERVICES AND CONCEPTS? LET ME SUMMARIZE FIRST AND THEN ELABORATE VERY BRIEFLY.

- MANY YOUNG ADULTS CONTINUE THEIR CARE IN PEDIATRIC SETTINGS.

- NEGATIVE RESULTS FROM THIS ARE MANY:

  -- SOME PHYSICIANS FOR ADULTS AND THEIR ASSOCIATES LACK MEDICAL EXPERTISE IN THE DIAGNOSES AT HAND.

  -- OVER-PROTECTIVENESS BY PEDIATRIC PROFESSIONALS INHIBITS INDEPENDENCE OF THE PATIENT.

  -- THERE IS A NEGATIVE MESSAGE OF SURVIVAL TO THE PATIENT IF HE FOREVER STAYS IN PEDIATRICS.

I SPENT A LOT OF MY PROFESSIONAL LIFE MAKING SURE THAT KIDS WITH SURGICAL PROBLEMS GOT A FAIR SHAKE IN AN ADULT WORLD. I THINK WE CAN CLAIM SUCCESS THERE.

BUT I MUST ADMIT THAT HAVING STRUGGLED TO BRING THAT ABOUT, I WAS ALWAYS EMBARRASSED TO FIND A PATIENT IN HIS/HER EARLY TWENTIES OCCUPYING A BED IN THE CHILDREN'S HOSPITAL OF PHILADELPHIA -- AS MUCH AS WE WANTED HIM/HER AND IN SPITE OF ALL WE HAD TO OFFER. THAT PATIENT WASN'T GETTING A FAIR SHAKE EITHER.

WE ARE NOT ASKING YOU TO CONSIDER A SERIES OF PROBLEMS WITH EASY SOLUTIONS. OUR CONCERNS ARE NOT AMENABLE TO A QUICK FIX.

A BASIC UNDERLYING DEFECT IN THE SYSTEM HAS TO DO WITH THE LACK OF A TRANSITION PROTOCOL FOR ORDINARY ADOLESCENTS FROM PEDIATRIC CARE TO ADULT SERVICES. PART OF THAT IS BECAUSE THE POPULATION IN GENERAL HAS ITS HEALTHEST YEARS IN THE DECADE AFTER ADOLESCENCE. EVEN INDIVIDUALS UNDER THE CARE OF A FAMILY PRACTITIONER HAVE NO NEED TO CALL ON HIM FOR YEARS. THEN WHEN AN ACUTE ILLNESS TRIGGERS THE RETURN TO THE HEALTH CARE SYSTEM, IT IS LIKELY THAT A DIFFERENT PHYSICIAN WILL BE CONSULTED.

HOW MUCH MORE DIFFICULT FOR THE YOUNGSTERS WITH SPECIAL NEEDS WHEN HIS/HER ACUTE ILLNESS DEMANDS ENTRY TO THE ADULT SYSTEM.

SOME OF YOU HAVE ALREADY IDENTIFIED SOME OF THE BARRIERS TO A SUCCESSFUL TRANSITION. ATTITUDINAL BARRIERS COME FIRST AND THEY INVOLVE PATIENT, PARENTS, THE PEDIATRIC CARE GIVEN AND HIS ADULT COUNTERPART. I DON'T BELIEVE YOU PEDIATRICIANS AND INTERNISTS OUT THERE ARE TYPICAL.

I DON'T WANT TO DISCUSS THIS EXHAUSTIVELY, BUT LET ME HIT SOME HIGHLIGHTS. I'VE BEEN INVOLVED FOR ENOUGH YEARS AND WITH ENOUGH YOUNGSTERS TO KNOW THEY ARE HAVING MORE TROUBLE THAN THEY NEED GROWING UP; THAT THEY DON'T HAVE ANY ENTHUSIASM TO BECOME INVOLVED IN THE PROBLEM OF TRANSITION BEYOND ACKNOWLEDGING IT AS A PROBLEM.

PARENTS UNDERSTANDABLY DON'T WANT TO LEAVE THE FAMILIARITY, SECURITY AND EXPERTISE OF WHAT THEY HAVE FOR THE UNKNOWN -- WHICH USUALLY TURNS OUT TO SUFFER GREATLY IN COMPARISON WITH THE KNOWN.

PEDIATRICIANS AND THEIR ASSOCIATES -- HAVING A TREMENDOUS INTEREST AND INVESTMENT IN THE RECIPIENT OF THEIR CARE, HAVE A PROPRIETARY INTEREST THAT ENCOURAGES THEM TO CLING TO THE PATIENT LONGER THAN THEY KNOW IS NECESSARY OR IN THE PATIENT'S BEST INTERESTS, -- EVEN THOUGH THE IMMEDIATE ADULT CARE SEEMS TO BE A STEP BACKWARD.

THE NEW RESPONSIBLE ADULT CARE GIVER HAS LOTS OF THINGS TO OVERCOME: FIRST, THE IDEA THAT PEDIATRICIANS PLAY MEDICAL GAMES WITH THEIR PATIENTS AND OVER-INDULGE THEIR PATIENT'S PARENTS. SECOND, THE TRUTH THAT THE PARENTS KNOW MORE ABOUT THE CHILD, HIS PROBLEM, AND THE GOALS OF HIS CARE THAN HE DOES. THIRD, THE IDEA THAT IT IS NOT UNREASONABLE FOR PARENTS TO BE ANXIOUS, TO EXPECT SATISFACTORY EXPLANATIONS, AND TO WANT TO BE PART OF ANY DECISION MAKING.

THERE IS ONE ASPECT OF THIS TRANSITION WHICH I THINK WE MUST ACCEPT AS A "GIVEN" WE PROBABLY CANNOT CHANGE. I SPEAK NOW -- VERY HONESTLY -- FROM LONG REPETITIVE PERSONAL EXPERIENCE.

THE ADULT CARE GIVER WILL PROBABLY NEVER HAVE THE SAME CREATIVE INTEREST THAT WAS THE PRICELESS INGREDIENT OF THE FORMER SITUATION, INDEED MAY HAVE BEEN THE ADHESIVE THAT HELD IT TOGETHER.

SOME DIAGNOSES I DEALT WITH REQUIRED 10 TO 15 YEARS OF CONSTANT ATTENTION TO ENSURE A MAXIMAL HABILITATION OF THE INFANT BECOMING A TODDLER, BECOMING A CHILD, BECOMING AN ADOLESCENT. I MOLDED THOSE YOUNGSTERS AS BEST I COULD INTO THE BEST THEY COULD BE -- ACADEMICALLY TO MY SKILLS, MY BELIEFS, MY EXPERIENCES, AND MY PREJUDICES. MY INTEREST WAS VERY PROPRIETARY.

BECAUSE OF OUR MOBILE SOCIETY, I INHERITED NEW PATIENTS -- BY REFERRAL -- WHEN THEY WERE HALFWAY -- OR MORE OR LESS -- THROUGH THEIR HABILITATION PROCESS. AND REMEMBER, I WAS AWARE OF THE PROBLEM AND I WAS TRYING.

THINK HOW DIFFICULT IT IS FOR THE RELUCTANT PHYSICIAN, AND I SENT SOME OF MY CHARGES ELSEWHERE AS WELL.

HERE'S THE CONFESSION -- I NEVER COULD MASTER QUITE THE SAME ENTHUSIASM, THE SENSE OF PROPRIETARY INTEREST IN AN INHERITED PATIENT AS I HAD IN MY OWN. AND I KNOW IT WAS THE SAME WITH MY PATIENTS THAT I REFERRED ELSEWHERE.

PART OF THIS IS DUE TO DIFFERENCES IN PHILOSOPHY AND TECHNIQUE AND SOME IS COMPETITIVE, AND I'M SURE THE SIN OF PRIDE IS IN THERE TOO. BUT WHATEVER -- THERE IS A DIFFERENCE.

MY POINT IS -- IF IT EXISTS WITHIN PEDIATRICS -- HOW MUCH MORE MIGHT IT BE EXPECTED IN A TRANSITION TO ADULT CARE.

IF TWO SCULPTORS, HALFWAY THROUGH A CREATION, HAVE TO FINISH THE OTHER'S WORK, IT SEEMS REASONABLE TO EXPECT THAT BOTH INTEREST AND RESULT WILL SUFFER. I DON'T THINK THE ANALOGY IS FAR-FETCHED.

EVEN TODAY -- AS HARD AS YOU MIGHT IMAGINE IT IS FOR A STRANGER TO BEAT HIS WAY THROUGH THE BUREAUCRACY AND FINALLY GET TO TALK TO ME PERSONALLY -- NOT A MONTH GOES BY THAT AN OLD PATIENT EVENTUALLY FINDS ME TO ASK ME TO INTERVENE IN A SITUATION WHERE ONE BARRIER OR ANOTHER HAS BECOME INSURMOUNTABLE.

MANY OF THESE ARE ATTITUDINAL PROBLEMS. REFUSAL TO EMPLOY A CURED JUVENILE PATIENT EVEN THOUGH CURED 15 - 20 YEARS. OTHERS ARE BUREAUCRATIC SITUATIONS -- RATHER LIKE CATCH 22 -- YOU CAN'T HAVE THUS OR THAT SERVICE UNTIL YOU CAN PROVIDE THUS AND SO -- BUT THUS AND SO CAN'T BE PROVED UNTIL THE SERVICE IS PROVIDED.

WELL I'VE BEATEN ATTITUDES INTO THE GROUND, AND I DON'T THINK IT IS NECESSARY FOR THIS AUDIENCE. THERE ARE OTHER POINTS I'D LIKE TO MAKE SUCH AS:

- KNOWLEDGE GAPS -- BE THEY TECHNIQUES, COMMUNITY RESOURCES -- EXPERIENCE AND OUTCOMES OF OTHERS -- AND INDEED WHAT IS ACHIEVABLE.

- CARE DELIVERY MODELS.

- COORDINATION WITH OTHER SERVICES.

- FINANCING OF CARE.

WE ARE TALKING ABOUT LABOR-INTENSIVE CARE, EXPENSIVE -- BUT REIMBURSEMENT SYSTEMS HAVE NOT CAUGHT UP WITH THIS FACT.

CHILDREN WITH SPECIAL NEEDS ENTERING THE ADULT SYSTEM ARE NOT OVERLY WELCOMED BECAUSE:

- THEY SHOULD MANY TIMES OVERSTAY THEIR DRG NORM.
- THEY MAY NOT BE COVERED -- ANY LONGER -- BY THEIR PARENT'S INSURANCE.
- IF EMPLOYED -- EVEN PART TIME -- THEY MAY BE PART OF THE WORKING POOR -- UNINSURED BUT NOT DESTITUTE ENOUGH TO BE ON WELFARE OR EVEN ELIGIBLE FOR MEDICAID.

FOR THE REST OF THIS CENTURY EVERYTHING YOU AND I DISCUSS IN REFERENCE TO MEDICINE, HEALTH CARE DELIVERY OR POLICY WILL MERELY BE SYMPTOMATIC OF THE OVERACHING TENSION BETWEEN OUR ASPIRATIONS FOR HEALTH CARE AND OUR RESOURCES TO PAY FOR THEM.

THE TWO POPULATIONS AT GREATEST RISK OF DISFRANCHISEMENT ARE THE ELDERLY AND CHILDREN. YOU WILL HAVE TO FIGHT HARDER THAN EVER FOR THE FUNDS TO CARE FOR SPECIAL NEEDS CHILDREN.

I DON'T EXPECT ANY ADMINISTRATION OR ANY CONGRESS TO ADDRESS THIS ISSUE ON THE CLEAR MERITS OF THE SITUATION -- IN SPITE OF THE NATION'S AFFLUENCE AND PROSPERITY. BUT THE DAY WILL COME WHEN THE BUSINESS COMMUNITY WILL CRY FOR HELP AS THE COST OF HEALTH CARE MAKES US NON-COMPETITIVE IN WORLD MARKETS. BE PREPARED FOR THAT DAY SO OUR SPECIAL NEEDS CHILDREN ARE NOT SHORT CHANGED AS THE HEALTH CARE DELIVERY SYSTEM IS REBUILT -- AS INDEED IT MUST BE.

THESE ARE THE ISSUES WE ASK YOU TO DISCUSS WITH US OVER THE NEXT TWO DAYS -- ALONG WITH ANY ADDITIONAL ONES FROM YOUR EXPERIENCE YOU WOULD LIKE TO BRING FORTH.

LET US CLEARLY IDENTIFY THE PROBLEMS AND PLAN CONCRETE EFFORTS WHICH EACH OF YOU CAN PURSUE WITHIN YOUR OWN ORGANIZATION. LET US THEN OUTLINE SOME EFFORTS WE CAN JOINTLY PURSUE TO KNOCK DOWN THE BARRIERS CURRENTLY PREVENTING OUR YOUNG PEOPLE FROM LIVING THEIR LIVES TO THE FULLEST.