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Our Commitment to the Disabled Child

By

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and

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(GREETINGS TO HOSTS, GUESTS)

I AM DELIGHTED TO SHARE YOUR PLATFORM AND YOUR ENTHUSIASM TODAY. YOUR ASSOCIATION FOR THE SEVERELY HANDICAPPED HAS BEEN ON THE LEADING EDGE OF THE THINKING IN THIS COUNTRY, RELATIVE TO THE CARE OF OUR CITIZENS WHO NEED THE BEST WE'VE GOT TO GIVE.

YOU ARE AN IMPORTANT PART OF OUR NATIONAL CONSCIENCE. YOU'VE CARRIED THAT RESPONSIBILITY WELL FOR THE PAST 10 YEARS. SPEAKING FOR MYSELF AND, I AM SURE, FOR THE THOUSANDS UPON THOUSANDS OF CITIZENS WHO KNOW YOUR WORK, I FULLY EXPECT YOU WILL BE AN EFFECTIVE NATIONAL CONSCIENCE FOR THE NEXT 10 YEARS AS WELL.

I'M USING THAT WORD "CONSCIENCE" FOR A PURPOSE. I WANT TO MAKE SURE YOU REMAIN AWARE, OVER THE NEXT SEVERAL MINUTES, THAT THERE <u>IS</u> SUCH A THING AS CONSCIENCE AND THAT IT IS IMPORTANT IN THE CONDUCT OF THE AFFAIRS OF GOVERNMENT. I BELIEVE THAT'S TRUE. I AM POSITIVE THAT MY COLLEAGUE, ASSISTANT SECRETARY MADELEINE WILL, ALSO BELIEVES THAT IS SO. AND I CAN ASSURE YOU THAT THE OFFICE OF THE SURGEON GENERAL OF THE UNITED STATES IS COMMITTED TO SERVICE TO THE HANDICAPPED "IN ALL GOOD CONSCIENCE."

NOW LET ME COMMENT BRIEFLY ON A TOPIC THAT IS ON YOUR MINDS TODAY ...THE SO-CALLED "BABY DOE" REGULATION. BUT I'M AFRAID MY COMMENTS WILL HAVE TO BE QUITE BRIEF.

AS YOU KNOW, OUR ORIGINAL PROPOSAL FOR A REGULATION TO COVER "BABY DOE" KINDS OF SITUATIONS WAS PUBLISHED LAST MARCH AND MET WITH A GREAT DEAL OF OPPOSITION. THE MATTER WENT BEFORE THE COURTS, JUDGE GERHARD GESELL RULED AGAINST THE GOVERNMENT'S PROCEDURE IN THIS MATTER, AND WE WENT BACK TO THE DRAWING-BOARD. ON JULY 5 WE PUBLISHED A REVISED VERSION OF THE PROPOSED "BABY DOE" REGULATION, CAREFULLY SPELLING OUT NOT ONLY WHAT WE <u>WERE</u> TRYING TO DO BUT ALSO WHAT WE WERE <u>NOT</u> TRYING TO DO. THE DEPARTMENT CALLED FOR A 60-DAY PERIOD FOR PUBLIC COMMENT. AS A RESULT, THE COURT CASE BECAME MOOT AND, WITH ALL SIDES AGREEING, THE CASE WAS WITHDRAWN AND DISMISSED.

BETWEEN JULY 5 AND SEPTEMBER 6 THE OFFICE OF CIVIL RIGHTS, WHICH IS THE SPONSOR OF THIS REGULATION, RECEIVED 16,000 COMMENTS. NOT MANY REGULATIONS PROPOSED BY THE GOVERNMENT GET THAT MUCH ATTENTION. FOR EXAMPLE, THE ORIGINAL "504" REGULATION, THE ONE THAT IS THE "HOST," SO TO SPEAK, FOR THE "BABY DOE" REGULATION, DREW A LITTLE MORE THAN 700 COMMENTS FROM THE PUBLIC BEFORE IT BECAME FINAL BACK IN MAY 1977.

I SHOULD NOTE, IN THIS CONTEXT, THAT THE GOVERNMENT WILL FINALLY DECIDE ON THIS REGULATION ON THE BASIS OF THE SUBSTANCE OF THE COMMENTS BEING SENT IN. WHILE THOUSANDS OF CARDS AND LETTERS DO INDICATE A MEASURE OF PUBLIC INTEREST, THE VOLUME ITSELF CANNOT BE A FACTOR IN THE FINAL DECISION BY OUR DEPARTMENT.

WITH THE REGULATIONS PROCESS AT THIS STAGE, IT IS VIRTUALLY IMPOSSIBLE FOR ME TO COMMENT ANY MORE THAN I HAVE ALREADY ON THE SPECIFIC "BABY DOE" PROPOSAL. BUT I CAN SAY ONE THING, BECAUSE I'VE SAID IT BEFORE. AND IT IS THIS:

> THE MERE ACT OF PUBLISHING THE REGULATION, AS IMPERFECT AS IT MIGHT BE -- AND THAT, OF COURSE, IS THE WHOLE ARGUMENT -- BUT JUST THE ACT OF PUBLICATION SEEMED TO BE ENOUGH TO CAUSE THE HEALTH PROFESSIONS, HEALTH PROGRAM ADMINISTRATORS, AND THE PUBLIC AT LARGE TO TAKE A SECOND AND MUCH CLOSER LOOK AT WHAT IS REALLY HAPPENING IN THE NEONATAL WARDS OF OUR COUNTRY.

NOW, I DO NOT MEAN TO BE AN ALARMIST. NOT FOR A MOMENT WOULD I WANT TO IMPLY THAT THE MEDICAL CARE WE GIVE OUR CHILDREN IS ANYTHING LESS THAN THE BEST. WE HAVE EVERY RIGHT TO BE PROUD OF OUR SYSTEM OF HEALTH AND MEDICAL CARE. IT IS THE BEST IN THE WORLD BECAUSE IT IS BASED UPON A TRULY SACRED PROPOSITION:

EVERY LIFE OF EVERY PERSON IN OUR SOCIETY IS IMPORTANT -- UNIQUELY IMPORTANT.

IT'S A PROPOSITION THAT AMERICANS HAVE STUBBORNLY REFUSED TO AMEND OR QUALIFY FOR MORE THAN 200 YEARS. AND WE SHOULD BE THANKFUL WE HAVE SUCH A LEGACY.

THIS BECOMES ESPECIALLY APPARENT TO ME WHEN I GO OVERSEAS. DURING MY 35 YEARS AS A PEDIATRIC SURGEON, I MADE MANY TRIPS TO NATIONS ON 5 CONTINENTS, USUALLY INVITED BY MY COLLEAGUES IN MEDICINE TO HELP THEM ESTABLISH PEDIATRIC SURGERY IN THEIR OWN COUNTRIES. AND SINCE BECOMING SURGEON GENERAL TWO YEARS AGO, I'VE HAD THE PRIVILEGE TO REPRESENT THE UNITED STATES AT MEETINGS OF THE WORLD HEALTH ORGANIZATION AND THE PAN AMERICAN HEALTH ORGANIZATION. AT THOSE MEETINGS I ALWAYS TRY TO MEET AND TALK WITH DELEGATES FROM MANY OTHER NATIONS -- BOTH "DEVELOPED" AND "DEVELOPING" NATIONS.

THEY ARE ALL TRYING TO DO BETTER THINGS FOR THEIR PEOPLE, BUT NOT ALL OF THEM ARE SUCCEEDING. AND I COME AWAY CONVINCED THAT IT'S NOT ONLY BECAUSE THEY LACK TRAINED PERSONNEL OR APPROPRIATE FACILITIES... AND IT'S NOT JUST THE LACK OF CLEAN WATER OR A BALANCED DIET...THAT'S NOT WHAT IS HOLDING BACK MANY COUNTRIES. THOSE THINGS ARE IMPORTANT, BUT THEY ARE NOT FUNDAMENTAL.

NO, WHAT REALLY HOLDS A COUNTRY BACK IS ITS HESITATION TO COMMIT SUFFICIENT RESOURCES TO THE SAVING OF EVERY LIFE IT HAS.

AMERICANS GROW UP KNOWING WE MUST NOT HESITATE. THAT ARTICLE OF CONSCIENCE IS WOVEN THROUGHOUT THE FABRIC OF OUR NATIONAL LIFE. NOW AND AGAIN WE MAY BE PUZZLED AS TO <u>WHAT</u> WE OUGHT TO DO TO SAVE OR ENHANCE A HUMAN LIFE. BUT WE ALL KNOW <u>WHY</u> WE OUGHT TO DO IT.

AND I HAVE TO SAY THAT THE "BABY DOE" REGULATION SEEMS TO HAVE STRUCK THAT CHORD IN OUR SOCIETY. IT DEALS WITH A VERY DIFFICULT PROBLEM, TO BE SURE. BUT THE FACT THAT IT IS A PROBLEM <u>AT ALL</u> IS TESTIMONY TO OUR AMERICAN HERITAGE OF BEING COMMITTED TO SAVE LIVES ...A COMMITMENT THAT IS CARRIED OUT EXPERTLY, GENEROUSLY, AND COMPASSIONATELY BY PEOPLE JUST LIKE THE ONES I'M ADDRESSING HERE TODAY.

EVER SINCE THE FIRST "BABY DOE" PROPOSAL WAS PUBLISHED, PROFESSIONALS HAVE BEEN THINKING AND WRITING ABOUT THE SO-CALLED "DILEMMAS" IN THE NEONATAL NURSERY, WHILE THE MEDIA HAVE TENDED TO COLLAPSE ALL THESE QUESTIONS INTO ONE SINGLE HEADLINE: "WHO SHOULD LIVE AND WHO SHOULD DIE?" THIS MAY SURPRISE YOU WHEN I SAY IT, BUT THESE ARE NOT DILEMMAS TO ME ANY MORE.

OVER THE YEARS I HAVE TRIED TO RECOGNIZE THE PROFOUND DIFFERENCE BETWEEN TREATMENT AIMED AT GIVING AN INFANT ALL THE LIFE TO WHICH IT'S ENTITLED AND TREATMENT AIMED AT PROLONGING THE ACT OF DYING. I WAS NOT ALONE IN SEEING THAT DIFFERENCE, ALTHOUGH IT WAS NOT ALWAYS FASHIONABLE TO TALK ABOUT IT IN LARGE PUBLIC MEETINGS. TODAY, THAT'S CHANGED. WE'RE TALKING AGAIN ABOUT ISSUES THAT GO TO THE MARROW OF OUR EXISTINCE AS HUMAN BEINGS. AND THAT KIND OF DEBATE CAN ONLY HELP US BE BETTER PEOPLE.

TODAY, OUR COLLEAGUES IN MEDICINE, EDUCATION, AND THE SOCIAL SERVICES ARE THINKING ABOUT THESE ISSUES WITH A GREAT DEAL MORE CARE, AS A RESULT OF THE "BABY DOE" REGULATION. I BELIEVE THAT THE "GRAY AREA" FOR DECISION-MAKING IS NOW A GOOD DEAL NARROWER THAN IT ONCE APPEARED TO BE FOR MANY HEALTH PROFESSIONALS. I THINK THEY ALSO SEE A BROADER BASE FOR MORE CLEAR-CUT DECISIONS IN THE NURSERY -- DECISIONS WITHOUT GUILT...COMPASSIONATE AND HUMANE DECISIONS...DECISIONS THAT FLOW FROM THE HIGHEST PRINCIPLES OF OUR PROFESSION.

FOR ME, THAT IS AN EXTRAORDINARY ACCOMPLISHMENT ALL BY ITSELF.

NOW LET ME TURN TO AN ISSUE THAT TRANSCENDS LAW AND REGULATION. IT IS THE PROBLEM OF PROVIDING REASONABLE, RESPONSIBLE SERVICE TO DISABLED NEWBORNS AND THEIR FAMILIES. HOW SHOULD WE DO THAT? WHAT ARE THE KINDS OF THINGS WE NEED TO KEEP IN MIND? MUCH OF WHAT I WILL SAY IS AFFECTED NOT ONE BIT BY LAW OR REGULATION. YOU CAN'T LEGISLATE PROFESSIONALISM...YOU CAN'T MANDATE COMMON SENSE...AND YOU CAN'T REGULATE COMPASSION.

THOSE ARE IMPORTANT WORDS THAT STAND FOR BEAUTIFUL CONCEPTS. BUT HOW DO WE BREATHE LIFE INTO THEM? FOR THE SEVERELY HANDICAPPED, THIS IS AN ESPECIALLY CRITICAL QUESTION. THEY NEED THE VERY BEST HUMAN SERVICE THAT IS AVAILABLE. NOW, HOW ARE THEY GOING TO GET IT?

I WANT TO APPROACH THE SUBJECT FROM THE VANTAGE-POINT I HAVE KNOWN BEST: THAT IS, AS A PHYSICIAN PERSONALLY DEALING WITH HANDICAPPED CHILDREN AND WITH THEIR FAMILIES, WITH THE HOSPITAL AND ITS RANGE OF PROFESSIONAL PERSONNEL, AND WITH THE COMMUNITY ITSELF -- THE ULTIMATE RESERVOIR OF HELP AND HOPE.

MORE SPECIFICALLY, I WANT TO MAKE A FEW OBSERVATIONS ON THE ROLES TO BE PLAYED BY THOSE DIFFERENT FORCES AT HAND.

FIRST, I THINK WE ALL NEED TO REMEMBER THAT -- DESPITE THE DIFFICULT NATURE OF OUR JOBS AND THE TERRIBLE PROBLEMS FACED BY SO MANY PATIENTS AND THEIR FAMILIES -- THE INEXORABLE DIRECTION OF INFANT AND CHILD HEALTH IN THIS COUNTRY IS TOWARD IMPROVED CARE AND BETTER OUTCOMES.

THE INFANT MORTALITY RATE FOR THE YEAR ENDING IN DECEMBER 1982 WAS 11.2 DEATHS PER 1,000 LIVE BIRTHS. THAT'S THE LOWEST IT HAS BEEN IN OUR HISTORY. THERE HAD BEEN SOME FEELING LATELY THAT WE MIGHT BE HITTING A PLATEAU, THAT THE CURVE WOULD BEGIN TO FLATTEN OUT AND WE'D BE CONFRONTED BY THE TRULY HARD-CORE ISSUES OF INFANT MORTALITY AND PERINATAL CARE IN THIS COUNTRY. BUT THE CURVE IS NOT FLATTENING OUT. IT IS STILL GRADUALLY GOING DOWN. WE HOPE TO SEE THE INFANT MORTALITY RATE COME DOWN TO 9 PER 1,000 LIVE BIRTHS BY THE END OF THIS DECADE. AND I BELIEVE WE'RE GOING TO MAKE IT.

APPARENTLY WE'RE DOING A FEW THINGS RIGHT, ALTHOUGH IT IS NEARLY IMPOSSIBLE TO IDENTIFY WHICH "THINGS" ACCOUNT FOR WHAT PORTION OF OUR SUCCESS. HENCE, IT IS VERY DIFFICULT TO SET PRIORITIES.

IN ADDITION, IT SEEMS CLEAR THAT MOST OF THE INFANT LIVES WE ARE SAVING ARE HEALTHY LIVES. THERE'S NO EVIDENCE SO FAR OF AN INVERSE RELATIONSHIP BETWEEN MORBIDITY AND MORTALITY. IN OTHER WORDS, THE INFANT MORBIDITY RATE IS NOT RISING AS THE INFANT MORTALITY RATE GOES DOWN. BUT, IN ALL CANDOR, WE STILL DON'T WHY.

BETWEEN 1970 AND LAST YEAR, FOR EXAMPLE, THE INCIDENCE OF SERIOUS NEURAL TUBE BIRTH DEFECTS SUCH AS ANENCEPHALY AND SPINA BIFIDA DROPPED BY MORE THAN 60 PERCENT. ON THE OTHER HAND, THE RATE FOR VENTRICULAR SEPTAL DEFECTS HAS TRIPLED. WE DON'T KNOW WHAT'S BEHIND THESE CHANGES, BUT THERE DOESN'T SEEM TO BE ANY CONNECTION WITH THE OVERALL INFANT MORTALITY RATE.

BUT WE DON'T NEED STATISTICAL CURVES GOING UP OR DOWN TO UNDERSTAND THE IMPACT OF A DISABLED INFANT UPON ITS PARENTS AND THE ATTENDING MEDICAL AND SOCIAL SERVICE STAFFS. NOR DO WE NEED A GREAT DEAL OF DOCUMENTATION TO KNOW THAT A DISABLED NEONATE EXACTS A HIGH COST IN BOTH EMOTIONS AND MONEY.

GIVING BIRTH IS A VERY COMPLEX EMOTIONAL, PSYCHOLOGICAL, AND PHYSICAL EVENT EVEN WITH THE DELIVERY OF A HEALTHY, NORMAL BABY. HOW MUCH MORE COMPLEX IT IS WHEN THE INFANT IS DISABLED. ALL THE PERSONS INVOLVED -- PARENTS, SIBLINGS, AND HOSPITAL STAFF -- SHARE THE TERRIBLE FEELINGS OF GUILT AND INADEQUACY.

BUT ULTIMATELY IT IS THE INFANT ITSELF WHO NEEDS THE UNDERSTANDING, THE AFFECTION, AND THE CARE TO GIVE IT ITS BEST CHANCE AT LIFE. THAT'S REALLY WHAT THE "BABY DOE" ISSUE IS ALL ABOUT, TOO. AND A NEWBORN CAN GET THAT CHANCE ONLY IF A HUMAN CLOSENESS HAS DEVELOPED BETWEEN BETWEEN PARENTS AND PHYSICIAN AND BETWEEN PARENTS AND OTHER HEALTH AND SOCIAL SERVICE PROFESSIONALS.

SOME PHYSICIANS ARE ABLE TO DO THIS. MUCH DEPENDS ON THEIR TRAINING, PERSONAL COMMITMENT, WORKLOAD, AND OTHER FACTORS. BUT IF A WARM AND TRUSTING RELATIONSHIP BETWEEN PHYSICIAN AND PARENTS IS NOT FORTHCOMING, THEN ADDITIONAL HELP FROM THE SOCIAL SERVICE AND NURSING STAFFS ARE ESSENTIAL.

SOME STUDIES HAVE INDICATED THAT BETTER THAN 95 PERCENT OF PARENTS OF HANDICAPPED INFANTS DO TAKE RESPONSIBILITY FOR THEIR CHILDREN. THEY TAKE THEM HOME AND ABSORB THEM INTO THEIR FAMILY LIVES. NINETY-FIVE PERCENT IS A SUBSTANTIAL FIGURE AND, BY ITSELF, IMPLIES A HIGH ORDER OF PRIORITY. IT WOULD SEEM THAT ANY COLLABORATIVE RELATIONSHIPS AT ANY LEVEL -- INSTITUTIONAL, COMMUNITY, OR STATE -- WOULD NEED TO SET ASIDE AS MANY RESOURCES AS POSSIBLE TO HELP THOSE PARENTS UNDERSTAND, LOVE, AND KEEP THEIR CHILD.

OF COURSE, MEDICAL AND SOCIAL SERVICES SHOULD NOT TAKE THE PLACE OF THE FAMILY. RATHER, THEY SHOULD BE USED TO HELP THE FAMILY SURVIVE AND FUNCTION...TO RENEW ITS STRENGTH AND FOSTER ITS COHESION. FOR THE FAMILY IS GOING TO PROVIDE THE LONG-TERM SUPPORT REQUIRED BY THE DISABLED INFANT.

THE FAMILY'S DAILY DECISIONS, ROUTINES, AND RELATIONSHIPS WILL TRANSLATE INTO THE SUPPORT, THE THERAPY, THE SPECIAL EDUCATION AND REHABILITATION EFFORTS, THE RECREATION, AND ALL THE OTHER SERVICES THAT HELP BRING ABOUT THE BEST POSSIBLE QUALITY OF LIFE FOR THE DISABLED CHILD.

BUT WE MUST NOT OVER-ROMANTICIZE THE FAMILY ROLE. THAT'S JUST AS HARMFUL AS IGNORING THE FAMILY ALL TOGETHER. THE CHANCE TO HELP FAMILIIES WITH DISABLED INFANTS CAN COME ONLY IF THE PARENTS ARE CAPABLE AND WANT IT TO HAPPEN. SOME PARENTS AREN'T CAPABLE...OR THEY DON'T WANT TO TAKE THE GAMBLE.

WE ALSO NEED TO RECOGNIZE THAT A SMALL PERCENTAGE OF OUR ADULT POPULATION IS NOT EMOTIONALLY OR MENTALLY COMPETENT. INDEED, THEY THEMSELVES REQUIRE SOCIETY'S ATTENTION. HENCE, THEIR CHILDREN MOST DEFINITELY NEED OUR HELP.

SOME PARENTS HAVE CHILDREN AND SURRENDER THEM AT ONCE, EITHER VOLUNTARILY OR INVOLUNTARILY. OTHER PARENTS ABANDON THEIR CHILDREN AS SOON AS THEY CAN. AND SOME KEEP THEIR CHILDREN...ONLY TO GIVE THEM UP LATER. I BELIEVE THIS LAST GROUP HAS NOT RECEIVED AS MUCH OF OUR ATTENTION AS IT MAY NEED.

AT THIS TIME WE DON'T HAVE A CLEAR IDEA OF THE NUMBER OF MOTHERS WHO TAKE HOME THEIR DISABLED INFANTS...TRY TO ABSORB ALL THE NEW INFORMATION...TRY TO COPE WITH THE PROBLEMS -- BUT ULTIMATELY DECIDE TO SURRENDER THEIR CHILDREN FOR ADOPTION OR INSTITUTIONALIZATION.

IT'S BEEN MY EXPERIENCE THAT MANY OF THESE PARENTS WOULD BE REWARDED A HUNDRED-FOLD BY THEIR CHILD, IF THEY COULD ONLY HOLD ON JUST A LITTLE LONGER OR BE GIVEN JUST A LITTLE MORE SUPPORT. AND THE CHILD, IN THE OVERWHELMING NUMBER OF SUCH CASES, WOULD ALSO HAVE A CHANCE AT A MORE FULFILLED AND FULFILLING LIFE. WHAT GOES WRONG? AND CAN WE DO ANYTHING ABOUT IT?

I THINK THERE ARE SOME THINGS WE CAN DO. AND, FROM MY OWN PERSONAL EXPERIENCE, I KNOW THEY WORK. THESE ARE TASKS THAT CUT ACROSS DISCIPLINES AND I OFFER THEM TO YOU TODAY BECAUSE OF THE SCOPE OF INTERESTS AND SKILLS YOU REPRESENT.

THE FIRST TASK, IT SEEMS TO ME, WOULD BE TO PREPARE THE PEDIATRIC AND SURGICAL STAFFS FOR POSSIBLE LONG-TERM RELATIONSHIPS WITH PARENTS.

MOST DELIVERIES IN THIS COUNTRY ARE TROUBLE-FREE AND MOST INFANTS ARE HEALTHY, SO IT IS UNDERSTANDABLE WHEN MEDICAL STAFFS ARE COURTEOUS AND CHEERFUL -- ALMOST BREEZY -- AND QUITE SKILLFUL AT KEEPING PATIENT RELATIONS BRIEF AND SUPERFICIAL. TO BE FAIR, I THINK MOST PATIENTS WOULD JUST AS SOON HAVE IT THAT WAY. AND PARENTS TAKE THEIR BABIES HOME WITH THE STRONG WISH THAT THEY MAY NEVER HAVE TO SET FOOT IN A HOSPITAL EVER AGAIN. AND I WOULD BE THE FIRST ONE TO SAY "AMEN" TO THAT.

BUT THEN THERE IS THE INFANT BORN WITH DOWN SYNDROME OR A DAMAGED ORGAN SYSTEM OR WITH A MISSING OR DEFORMED LIMB -- OR ONE OF ANY NUMBER OF OTHER DISABLING CONDITIONS. IN THOSE CASES, THE PARENTS TURN FIRST TO THE MEDICAL STAFF AND THE QUESTIONS COME POURING OUT:

WHAT DOES IT MEAN?...

WILL THE CHILD LIVE?...

WHAT KIND OF LIFE WILL THE CHILD HAVE?...

IS IT THE RESULT OF SOMETHING WE DID?

...OR DID IT HAPPEN BECAUSE WE DIDN'T DO SOMETHING?

AT THAT POINT, THE PHYSICIAN-PATIENT RELATIONSHIP IS NO LONGER CASUAL OR SHORT-TERM. THE PHYSICIAN HAS TO TRANSLATE COMPLICATED MEDICAL TERMINOLOGY INTO WORDS A PARENT WILL UNDERSTAND AND NOT FEAR. THE PARENTS MUST BE ABLE TO ABSORB AND PROCESS THIS NEW INFORMATION, IN ORDER TO RATIONALLY TACKLE FAMILY, FINANCIAL, EMOTIONAL, AND OTHER ISSUES LATER ON.

PRECISELY AT THIS TIME WE NEED TO OBSERVE ONE BASIC RULE: NO MATTER HOW SERIOUS THE INFANT'S CONDITION AND NO MATTER HOW IT MAY AFFECT THE PHYSICIAN, THE PHYSICIAN MUST NOT IN ANY WAY TRANSMIT A SENSE OF HOPELESSNESS OR FUTILITY OR, IN EFFECT, "GO INTO MOURNING" FOR A CHILD WHO IS STILL VERY MUCH ALIVE, HOWEVER SEVERE ITS DISABILITY.

WE ARE OUTRAGED AT PARENTS WHO PHYSICALLY ABANDON THEIR CHILDREN. AND I AM OUTRAGED AT PHYSICIANS WHO INTELLECTUALLY ABANDON THEIR PATIENTS. NO MATTER HOW SOPHISTICATED OUR DIAGNOSTIC TECHNOLOGY, IT CAN STILL BE WRONG. BY THE SAME TOKEN, THE SURVIVAL POWER OF THE HUMAN BEING -- EVEN IN ITS TINY NEWBORN STATE -- CAN BE TRULY AWESOME.

BUT LET ME EMPHASIZE THAT RESTRAINING ONE'S SELF FROM VOICING HOPELESSNESS IS NOT THE SAME THING AS OFFERING FALSE HOPES TO CONFUSED AND FRIGHTENED PARENTS. WE NEED TO BE CAUTIOUS BUT ALSO HONEST, AND OBJECTIVE WITH PARENTS.

AND WE NEED TO BUILD ON THEIR STRENGTHS. AS I MENTIONED A MOMENT AGO, ONLY A VERY SMALL PERCENTAGE OF AMERICANS HAVE CERTAIN PERSONAL AND SOCIAL INADEQUACIES. ON THE OTHER HAND, THE OVERWHELMING MAJORITY OF AMERICANS HAVE THE STRENGTH TO CARRY THEM THROUGH THE MOST DIFFICULT HUMAN TRAUMA, WHETHER PHYSICAL, PSYCHOLOGICAL, OR EMOTIONAL.

I BELIEVE THERE ARE WAYS TO TRAIN MEDICAL STAFF -- PHYSICIANS OF ALL AGES, I MIGHT ADD -- TO HELP THEM PUT ASIDE THEIR SUPERFICIAL, BREEZY MANNER AND SETTLE DOWN TO A CLOSE...PERSONAL...COMPASSIONATE ...AND MAYBE PROLONGED RELATIONSHIP WITH PARENTS SETTING OUT ON A LONG AND INTRICATE JOURNEY IN HUMAN GROWTH.

WE NEED TO MAKE THIS TRAINING AVAILABLE TO <u>YOUNG</u> PHYSICIANS IN PARTICULAR. THEY WILL HAVE JUST COME FROM AN EDUCATIONAL SYSTEM THAT MEASURES SUCCESS ALMOST EXCLUSIVELY IN TERMS OF ONE'S ABILITY TO CURE OR REPAIR PATIENTS AND RETURN THEM TO A SO-CALLED "NORMAL" STATE. BUT MANY DISABLED NEONATES CANNOT BE "CURED" OR "REPAIRED." THEY MAY NEVER BE "NORMAL" FOR THE REST OF THEIR LIVES -- AND THEIR VERY LIVES MAY BE BRIEF. OUR YOUNG MEN AND WOMEN COMING INTO MEDICINE NEED TO UNDERSTAND THAT AND COME TO TERMS WITH IT PERSONALLY AND PROFESSIONALLY.

A SECOND TASK WOULD BE TO EXPAND AND STRENGTHEN THE FACILITATING SKILLS OF OUR SOCIAL SERVICES PERSONNEL. I MAY HAVE MENTIONED MUCH TOO CASUALLY THE MEETINGS BETWEEN PHYSICIANS AND PARENTS. BELIEVE ME, THESE ARE NOT CASUAL EVENTS. THE SETTING AND THE TIMING AND THE PEOPLE INVOLVED MUST ALL BE JUST RIGHT. AND ALL PARTIES MUST HAVE THE TIME TO WORK THROUGH AND COMPREHEND THE MOST COMPLEX, SENSITIVE INFORMATION. AND NOT ALL OF IT IS MEDICAL.

IT'S BEEN MY EXPERIENCE THAT MOST PEOPLE ARE ONLY VAGUELY AWARE OF CERTAIN SOCIAL SERVICE OR HEALTH AGENCIES. MOST PEOPLE ARE NOT EVEN VERY FAMILIAR WITH THE ONES THEY MAY HAVE CONTRIBUTED MONEY TO. AND WHEN FACED BY THE IMMEDIATE NEED TO GET INFORMATION, APPLY FOR HELP, MAKE CONNECTIONS, REQUEST RESOURCES, OR MAKE DECISIONS -- MUCH OF THEIR PRIOR KNOWLEDGE IS OF NO USE AT ALL.

EVEN THOSE PARENTS WHO MAKE THE COMMITMENT TO CARE FOR THEIR CHILD AND GIVE IT ALL THE LOVE IT NEEDS...EVEN <u>THEY</u> MAY BE OVER-WHELMED BY THE OFTEN BYZANTINE COMPLEXITY OF OUR HEALTH AND SOCIAL SERVICE DELIVERY SYSTEM. SOCIETY ITSELF SEEMS TO BE CONSPIRING AGAINST THEIR OWN SENSE OF HUMANITY.

IF THERE IS ANY PROBLEM TO BE ADDRESSED AT A MEETING SUCH AS THIS, IT IS CERTAINLY THIS ONE -- A PROBLEM AS OLD AS CIVILIZATION ITSELF, I KNOW -- BUT IT IS THE PROBLEM OF GREATEST CONSEQUENCE FOR THOUSANDS OF FAMILIES. MANY COMMUNITY AND STATE SERVICES ARE STILL ORGANIZED ACCORDING TO THE PERCEPTIONS AND THE CONVENIENCE OF THE PEOPLE WHO <u>PROVIDE</u> THE SERVICE, NOT OF THE ONES WHO <u>NEED</u> IT. AND THIS CAN BE A DEVASTATING PROBLEM FOR MANY PARENTS WHO WANT TO SUCCEED WITH THEIR DISABLED CHILD.

IN MY PREVIOUS ROLE AS A PEDIATRIC SURGEON, I FREQUENTLY WORKED SIDE-BY-SIDE WITH PARENTS, NEGOTIATING HELP FROM A WIDE NETWORK OF PRIVATE AND PUBLIC, FREE AND FEE-FOR-SERVICE PROVIDERS. BUT I CAN TELL YOU IT IS NOT A ROLE FOR A SURGEON. WE'RE JUST NOT VERY GOOD AT IT. WE DON'T REALLY KNOW WHAT'S AVAILABLE.

IT'S ONLY FAIR TO SAY IN MY OWN DEFENSE, HOWEVER, THAT A NUMBER OF TODAY'S BUILT-IN MEDICAL AND SOCIAL SERVICES WERE NOT AVAILABLE WHEN I STARTED PRACTICE, SOME 35 YEARS AGO. AND I MUST SAY THAT THE SOCIAL SERVICES STAFF AT THE CHILDREN'S HOSPITAL OF PHILADELPHIA IS JUST FIRST-RATE.

I WOULD OFFER ONE <u>CAVEAT</u>, HOWEVER. THE SOCIAL SERVICES ROLE IS NOT OPEN-ENDED. IT CAN HELP MAKE GOOD THINGS COME TO PASS, BUT IT CANNOT <u>INSURE</u> THAT GOOD THINGS WILL COME TO PASS. FAMILIES -- LIKE INDIVIDUALS -- HAVE RICH AND VARIED BIOGRAPHIES:

THEIR FORTUNES RISE AND FALL.

CHILDREN DO OR DO NOT GET ALONG WITH EACH OTHER.

A MOTHER MAY OR MAY NOT DEVELOP A STRONG BOND WITH HER CHILDREN.

HUSBANDS AND WIVES MAY OR MAY NOT CLEAVE TO EACH OTHER TILL DEATH.

AND LET'S NOT FORGET THAT THE DISABLED INFANT...ADOLESCENT... YOUNG ADULT...AND ADULT IS AN EVOLVING HUMAN BEING, NEVER PRECISELY THE SAME FROM ONE DAY TO THE NEXT.

THESE ARE IMPORTANT POINTS TO REMEMBER, SINCE SERVICE WORKERS ARE VULNERABLE TO THE "BURN-OUT" SYNDROME, WHICH CAN COME FROM REPEATED PERCEPTIONS OF FAILURE. YET, IN MANY CASES, THOSE PERCEPTIONS ARE WRONG. WE MUST NOT EQUATE GROWTH AND EVOLUTION WITH "FAILURE."

I DON'T PRETEND TO KNOW WHERE THE DIVIDING LINE IS. MAYBE THERE JUST ISN'T ONE...MAYBE EACH PERSON HAS TO FIND HIS OR HER OWN. BUT CLEARLY, IN THIS AREA OF PROVIDING SERVICE TO DISABLED CHILDREN AND THEIR PARENTS, EACH PROFESSIONAL NEEDS TO SET SOME LIMIT ON HOW MUCH OF ONE'S SELF CAN BE SAFELY INVESTED IN OTHERS, WITHOUT RUNNING THE RISK OF LOSING ONE'S OWN PERSONA ALTOGETHER.

PERSONALLY, I AM MORE LIKELY TO TRUST PEOPLE WHO KNOW THEIR OWN VALUE, BECAUSE THEY ARE MORE LIKELY TO APPRECIATE MINE.

A THIRD TASK FOR US ALL, AND THE LAST ONE I WILL MENTION TODAY, IS THE NEED TO CONTROL -- RATHER THAN BE CONTROLLED BY -- THE NEW TECHNOLOGY OF MEDICINE AND HEALTH CARE. TO MAKE MY POINT, I WILL USE ONE OF THE MOST DRAMATIC EXAMPLES IN THE FIELD OF NEONATOLOGY TODAY: THE USE OF THE RESPIRATOR FOR DISABLED, DEPENDENT CHILDREN.

EARLIER ON, I MENTIONED THAT THE INFANT MORTALITY RATE WAS DECLINING AND, SINCE THE MORBIDITY RATE IS NOT TURNING SHARPLY UP, MOST OF THE BABIES WE'RE SAVING ARE HEALTHY BABIES. LIKE A LOT OF OTHER SPEAKERS, I TOO MAY HAVE OVERSIMPLIFIED THE MATTER. SO LET ME SET THE RECORD STRAIGHT.

A NUMBER OF THE INFANTS WE'RE SAVING ARE PREMATURE OR LOW-BIRTH-WEIGHT BABIES OR ARE IMMATURE IN SOME ASPECT OF THEIR DEVELOPMENT AND MAY DEMONSTRATE RESPIRATORY DISTRESS. THEY'RE USUALLY TAKEN IMMEDIATELY TO AN INFANT INTENSIVE CARE UNIT AND PUT ON A RESPIRATOR. HAD THEY BEEN BORN A FEW YEARS AGO, THESE BABIES WOULD NOT HAVE SURVIVED. TODAY THEY ARE ALIVE. BUT THEY REPRESENT A NEW CATEGORY OF DISABLED CHILD: THEY ARE DISABLED BECAUSE THEY CAN MAKE USE OF THE I.I.C.U. TECHNOLOGY.

THE COST IS VERY HIGH, NOT ONLY IN DOLLARS BUT IN FAMILY STRESS. THE CHILD IS DENIED THE INITIAL, VITAL ATTENTION OF ITS MOTHER. OPPORTUNITIES FOR EARLY BONDING ARE GONE. THE ENTRY OF THAT CHILD INTO ITS FAMILY IS DELAYED. DEPENDING UPON THE CIRCUMSTANCES, FOR SOME CHILDREN IT MAY BE DELAYED FOREVER.

IN MY FORMER ROLE AS A PEDIATRIC SURGEON, MY I.I.C.U. COLLEAGUES AND I, TAKING A PAGE OUT OF THE EXPERIENCE IN FRANCE, LOOKED INTO THE SITUATION AND WE DISCOVERED THAT THE TECHNOLOGY ALREADY EXISTED -- AND IT COULD BE FURTHER REFINED -- TO PROVIDE RESPIRATOR SUPPORT FOR MOST CHILDREN IN THEIR OWN HOMES. BUILDING ON THAT KNOWLEDGE, WE HELD A SURGEON GENERAL'S WORKSHOP ON HANDICAPPED CHILDREN AND THEIR FAMILIES, LAST DECEMBER AT THE CHILDREN'S HOSPITAL OF PHILADELPHIA. IN THE COURSE OF THAT MEETING WE OUTLINED SEVERAL BROAD PRINCIPLES FOR HELPING THOSE CHILDREN AND THEIR FAMILIES AND THE SPECIFIC KINDS OF SERVICES TO BE PROVIDED...SERVICES SUCH AS PHYSIOTHERAPY, SPECIAL EDUCATIONAL SERVICES, OCCUPATIONAL THERAPY, AND SPECIFIC NURSING CARE.

THE SAVINGS ARE NOT JUST IN DOLLARS. THERE ARE ALSO HUMAN SAVINGS, SUCH AS A POSSIBLE REDUCTION IN THE ENORMOUS EMOTIONAL AND PSYCHOLOGICAL BURDENS CARRIED BY THE CHILD AND ITS FAMILY. I WOULD ADD THE DIVIDENDS OF FAMILY COHESION AND GROWTH, THE STRENGTHENING OF PARENT-CHILD AND SIBLING RELATIONSHIPS, AND THE VERY SPECIAL DIVIDEND OF FAMILY CARE AND LOVE.

WE HAVE TO SET GOALS FOR THE IMPROVEMENT OF THIS NEW RESPIRATOR TECHNOLOGY. IT SHOULD BE REDUCED IN SIZE, SIMPLE ENOUGH FOR LAY-PERSONS TO OPERATE, AND IT SHOULD BE PORTABLE AND FLEXIBLE ENOUGH TO ADJUST TO DIFFERENT KINDS OF LIVING ARRANGEMENTS.

WE NEED TO SET THE SAME GOALS FOR OUR MEDICAL, EDUCATIONAL, AND SOCIAL SERVICES PERSONNEL:

- THEY NEED TO UNDERSTAND THAT THE MOVEMENT OF A CHILD OUT OF THE HOSPITAL AND INTO ITS OWN HOME SHOULD BE ACCOMPLISHED AS QUICKLY AS POSSIBLE.

- THEY NEED TO PREPARE THE FAMILY, VOLUNTARY AGENCIES, INSURERS, AND THIRD-PARTY PAYORS.

- THEY NEED TO OPEN LINES OF EMERGENCY COMMUNICATION.

IN OTHER WORDS, THEY HAVE TO TAKE SERIOUSLY THIS NEW HOME-CARE OPTION AND CONVEY THEIR BELIEF IN IT TO THE PARENTS OF THEIR RESPIRATOR-DEPENDENT PATIENTS.

WE AREN'T GOING TO MOVE ALL OUR RESPIRATOR-DEPENDENT CHILDREN OUT OF INTENSIVE CARE AND BACK INTO THEIR HOMES. BUT WE NEED TO MAKE A START. AND IN DOING THAT, WE NEED TO DO THE SAME KIND OF COLLABORATIVE PLANNING AND THE SAME DEGREE OF PROFESSIONAL TRAINING THAT'S REQUIRED IN OTHER AREAS OF MEDICAL, EDUCATIONAL, AND SOCIAL SERVICE.

I THINK IT CAN BE DONE. BUT MORE THAN THAT, I BELIEVE IT <u>HAS</u> TO BE DONE, IF WE INTEND TO HONOR OUR BASIC COMMITMENT TO LIFE WITH THE HELP OF TECHNOLOGY.

I'VE TAKEN UP A GREAT DEAL OF YOUR TIME AND I DO NOT WANT TO IMPEDE THE FLOW OF THIS PROGRAM. THEREFORE, I WILL CLOSE THESE REMARKS WITH A LITTLE STORY OF A PERSONAL EXPERIENCE I HAD NOT LONG AGO.

I HAD BEEN INVITED TO LECTURE AT YORK UNIVERSITY IN TORONTO ON THE SURGEON'S ROLE IN THE CARE OF THE DISABLED NEWBORN. WHILE PREPARING MY NOTES, I CONSULTED WITH THE MOTHER OF A FORMER PATIENT OF MINE, A CHILD BORN WITH MULTIPLE CONGENITAL DEFECTS. I ASKED HER TWO QUESTIONS. I WANT TO REPEAT THEM -- AND HER ANSWERS -- FOR YOU TODAY.

FIRST, I ASKED HER, "WHAT WAS THE <u>WORST</u> THING THAT HAS EVER HAPPENED TO YOU IN YOUR LIFE?"

SHE ANSWERED, "HAVING OUR SON BORN WITH ALL THOSE DEFECTS THAT REQUIRED 37 OPERATIONS TO CORRECT."

I WASN'T SURPRISED BY HER ANSWER, SINCE I HAD PERFORMED 22 OF THOSE 37 OPERATIONS. BUT I ALSO KNEW SHE HAD A STRONG FAMILY, A DEVOTED HUSBAND, AND THREE OTHER CHILDREN WHO WERE BORN HEALTHY AND HAVE BEEN LOVING SIBLINGS TO HER DISABLED SON. SO I ASKED HER, "ALL RIGHT, NOW WHAT WAS THE <u>BEST</u> THING THAT EVER HAPPENED IN YOUR LIFE?"

AND SHE ANSWERED, "HAVING OUR SON BORN WITH ALL THOSE DEFECTS THAT REQUIRED 37 OPERATIONS TO CORRECT."

THAT WONDERFUL WOMAN REMINDED ME -- YET AGAIN -- THAT OUR HOMES ARE FILLED WITH LOVE...AND COURAGE...AND UNDERSTANDING. AND THEY ARE GOOD HOMES FOR ALL OUR CHILDREN.

THANK YOU.

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