

0162T

ORIGINAL

OUR COMMITMENT TO THE DISABLED CHILD

BY

C. EVERETT KOOP, MD

SURGEON GENERAL

AND

DEPUTY ASSISTANT SECRETARY FOR HEALTH

PRESENTED TO THE CONFERENCE ON IMPROVING SERVICES

TO HANDICAPPED CHILDREN THROUGH

STATE/LOCAL COLLABORATION

WASHINGTON, D.C.

JUNE 2, 1983

(GREETINGS TO HOSTS, GUESTS)

IT IS A DISTINCT PLEASURE TO JOIN YOU TODAY TO TAKE PART IN THIS CONFERENCE. I HAVE A GOOD FEELING ABOUT THIS CONFERENCE:

IT'S HIGHLY PROFESSIONAL...

THE AGENDA IS PACKED WITH PRACTICAL APPLICATIONS OF AN IMPORTANT IDEA...

AND THE HUMAN FACTORS -- THE CHILDREN THEMSELVES AND THEIR FAMILIES -- HAVE NOT BEEN OVERLOOKED.

HOW MANY TIMES HAVE WE GONE TO MEETINGS DEALING WITH BASIC, HUMAN PROBLEMS ONLY TO FIND THAT THE ORGANIZERS SOMEHOW LEFT THE REAL "PEOPLE PROBLEMS" OUT OF THE PROCEEDINGS. FORTUNATELY, THAT'S NOT THE CASE HERE. AND FOR THAT -- AS WELL AS FOR THE ENTIRE PROGRAM -- I WANT TO EXTEND MY PERSONAL WORD OF THANKS TO EVERYONE WHO HAD A HAND IN THE ORGANIZING.

I LOOKED OVER THE AGENDA SEVERAL WEEKS AGO AND I WONDERED -- WITH SUCH A GOOD RANGE OF VIEWS AND EXPERIENCES REGARDING STATE-LOCAL COLLABORATION -- WHAT COULD MY CONTRIBUTION POSSIBLY BE? MODESTY WOULD DICTATE THAT I BRING YOU GREETINGS -- AND THEN JUST SIT DOWN.

BUT I CAN'T DO THAT. I CANNOT RISK THE CENSURE FROM MY FELLOW SURGEONS. WE'RE NOT KNOWN FOR BEING SHY AND RETIRING...AND I HAVE NO BUSINESS STARTING A NEW TREND. SO, WITH YOUR KIND INDULGENCE, I WILL PRESS AHEAD, KNOWING FULL WELL THAT I MIGHT BE GILDING THE OTHERWISE VERY NICE LILY THAT IS YOUR CONFERENCE PROGRAM.

FIRST, I WANT TO SAY JUST A WORD ABOUT A SUBJECT THAT I AM SURE IS ON THE MINDS OF MANY HERE TODAY. IT'S THE SO-CALLED "BABY DOE" REGULATION. AS YOU KNOW, THE MATTER IS BEFORE THE COURTS, AND IN THE MEAN-TIME WE ARE MEETING WITH A NUMBER OF GROUPS TO SEE HOW WE MIGHT REACH AN UNDERSTANDING THAT WOULD ALLOW THE PUBLIC BUSINESS TO GO FORWARD AND STILL GUARANTEE THAT CHILDREN WILL BE PROTECTED. THIS MAKES IT DIFFICULT -- VIRTUALLY IMPOSSIBLE -- FOR ME TO COMMENT ON THE SUBSTANCE OF THE REGULATION.

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, THE PROGRAM ADMINISTRATORS, AND THE PUBLIC AT LARGE INTO TAKING A SECOND AND MUCH CLOSER LOOK AT WHAT IS REALLY HAPPENING IN THE PEDIATRIC WARDS OF OUR COUNTRY.

I DO NOT 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 FOR THAT AS WELL.

THIS WAS ESPECIALLY APPARENT TO ME EARLY LAST MONTH. I WAS IN GENEVA, SWITZERLAND, AS A MEMBER OF THE AMERICAN DELEGATION TO THE ANNUAL WORLD HEALTH ASSEMBLY. AS AT PREVIOUS ASSEMBLIES, I TOOK THE OPPORTUNITY TO MEET AND TALK WITH A NUMBER OF 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 CAME 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 HOLDS BACK MANY COUNTRIES. THOSE THINGS ARE IMPORTANT, BUT THEY ARE NOT FUNDAMENTAL. RATHER, IT IS A NATION'S HESITATION TO COMMIT SUFFICIENT RESOURCES TO THE SAVING OF EVERY LIFE IT HAS.

AMERICANS GROW UP KNOWING WE MUST NOT HESITATE. THAT PRINCIPLE IS WOVEN THROUGHOUT THE FABRIC OF THE AMERICAN ETHOS. WE MAY BE PUZZLED AS TO WHAT WE OUGHT TO DO TO SAVE OR ENHANCE A HUMAN LIFE. BUT WE ALL KNOW WHY 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. BUT THE FACT THAT IT IS A PROBLEM AT ALL IS TESTIMONY TO OUR

AMERICAN HERITAGE OF FULFILLING A COMMITMENT TO SAVE LIVES, A COMMITMENT THAT IS CARRIED OUT EXPERTLY, GENEROUSLY, AND COMPASSIONATELY BY PEOPLE JUST LIKE THE ONES HERE TODAY.

PROFESSIONALS ARE NOW THINKING AND WRITING ABOUT THE SO-CALLED "DILEMMAS" IN THE NEONATAL NURSERY. THE MEDIA TEND TO COLLAPSE ALL THESE QUESTIONS INTO ONE SINGLE HEADLINE: "WHO SHOULD LIVE AND WHO SHOULD DIE?" BUT FOR ME, THESE ARE NOT DILEMMAS 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.

PEOPLE ARE THINKING ABOUT THESE ISSUES WITH A GREAT DEAL MORE CARE, AS A RESULT OF THE "INFANT DOE" REGULATION. I BELIEVE THAT THE "GRAY AREA" FOR DECISION-MAKING IS NOW A GOOD DEAL NARROWER THAN IT MIGHT HAVE 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 THE SUBSTANCE OF THIS CONFERENCE, THE NATURE OF COLLABORATION IN CARING FOR THE HANDICAPPED CHILD. I WANT TO APPROACH THE SUBJECT FROM A 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 12 MONTHS ENDING WITH FEBRUARY 1983 -- OUR LATEST PROVISIONAL FIGURE -- STANDS AT 11.2 DEATHS PER 1,000/LIVE BIRTHS. THERE HAD BEEN SOME FEELING IN THE PAST YEAR OR SO 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.

APPARENTLY WE'RE DOING A FEW THINGS RIGHT, ALTHOUGH IT IS NEARLY IMPOSSIBLE TO IDENTIFY WHICH SPECIFIC "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 HAVE NOT DONE THE KIND OF RESEARCH THAT CAN TELL US WHY. WE ARE STILL FUNCTIONING ON INSTINCT...ON THE VISCERAL RESPONSES OF PERINATALOGISTS.

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, SIBLING, 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 SO THAT IT WILL HAVE A CHANCE AT LIFE. BUT THE BABY WILL GET THAT CHANCE ONLY IF A HUMAN CLOSENESS HAS DEVELOPED BETWEEN BETWEEN PARENTS AND PHYSICIAN AND BETWEEN PARENTS AND OTHER HEALTH PROFESSIONALS.

SOME PHYSICIANS ARE ABLE TO DO THIS. NATURALLY, 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 STAFF IS ESSENTIAL.

SOME STUDIES HAVE INDICATED THAT BETTER THAN 95 PERCENT OF PARENTS OF HANDICAPPED INFANTS DO TAKE RESPONSIBILITY FOR THEIR CHILDREN, TAKE THEM HOME, AND TRY TO ABSORB THEM INTO THEIR FAMILY LIFE. THAT IS A SUBSTANTIAL FIGURE AND, BY ITSELF, IMPLIES AN ORDER OF PRIORITY. IT

WOULD SEEM THAT ANY COLLABORATIVE RELATIONSHIPS AT ANY LEVEL -- INSITU-
TIONAL, 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, MEDICINE AND SOCIAL SERVICE 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 IT
WILL BE THE FAMILY THAT WILL 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 RECREATIONAL EFFORTS, AND ALL THE OTHER SERVICES
THAT CAN HELP BRING ABOUT THE BEST POSSIBLE QUALITY OF LIFE FOR THE
DISABLED CHILD.

BUT THE CHANCE TO HELP THESE FAMILIIES CAN COME ONLY IF THE PARENTS
ARE CAPABLE AND WANT IT TO HAPPEN. SOME PARENTS AREN'T...AND THEY
DON'T WANT TO TAKE THE GAMBLE. ALSO, WE NEED TO RECOGNIZE THAT A SMALL
PERCENTAGE OF OUR ADULT POPULATION IS NOT EMOTIONALLY OR MENTALLY COM-
PETENT. INDEED, THEY THEMSELVES, REQUIRE SOCIETY'S ATTENTION. 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 THEM...THEN 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 NUMBERS OF MOTHERS WHO TAKE HOME THEIR DISABLED INFANTS...TRY TO ABSORB ALL THE NEW INFORMATION...TRY TO COPE WITH THE PROBLEMS -- BUT ULTIMATELY 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 WILL 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. MOST 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 SPINA BIFIDA...THERE'S THE CHILD WITH A CONGENITAL BIRTH DEFECT -- A DAMAGED ORGAN SYSTEM, 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?...WHAT'S THE PROGNOSIS FOR LIFE?...WHAT KIND OF LIFE WILL THE CHILD HAVE?...IS IT THE RESULT OF SOMETHING WE DID? ...IS IT 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 CAN 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.

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, 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; BUT THE OVERWHELMING MAJORITY HAVE THE STRENGTH TO CARRY THEM THROUGH THE MOST DIFFICULT OF HUMAN TRAUMA.

I BELIEVE THERE ARE WAYS TO TRAIN MEDICAL STAFF -- PHYSICIANS OF ALL AGES, I MIGHT ADD -- TO HELP THEM PUT ASIDE THEIR SUPERFICIAL MANNER, WHEN THE NEED IS CLEAR, 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 YOUNG PHYSICIANS IN PARTICULAR. THEY WILL HAVE JUST COME FROM AN EDUCATIONAL SYSTEM THAT MEASURES SUCCESS ALMOST EXCLUSIVELY IN TERMS OF CURING AND REPAIRING PATIENTS AND RETURNING 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. THEIR 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. BUT 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. EVEN THE ONES THEY'VE CONTRIBUTED TO ARE NOT ALWAYS COMPLETELY FAMILIAR TO MOST PEOPLE. AND WHEN FACED BY THE IMMEDIATE NEED TO GET INFORMATION, APPLY FOR HELP, MAKE CONNECTIONS, REQUEST RESOURCES, MAKE DECISIONS -- MUCH OF THEIR KNOWLEDGE BECOMES DISJUNCTIVE.

EVEN THOSE PARENTS WHO MAKE THE COMMITMENT TO CARE FOR THEIR CHILD AND GIVE IT ALL THE LOVE IT NEEDS...EVEN THEY MAY BE OVERWHELMED BY THE OFTEN BYZANTINE COMPLEXITY OF OUR HEALTH AND SOCIAL SERVICE DELIVERY SYSTEM. SOCIETY MAY CONSPIRE AGAINST THEIR HUMANITY.

IF THERE IS ANY PROBLEM TO BE ADDRESSED AT A CONFERENCE 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 PROVIDE THE SERVICE, NOT OF THE ONES WHO NEED 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, 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 ADD, 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 TODAY IS JUST FIRST-RATE.

I WOULD OFFER ONE CAVEAT, HOWEVER THE ROLE OF THE SOCIAL SERVICES IS NOT OPEN-ENDED. YOU CAN HELP MAKE GOOD THINGS COME TO PASS, BUT YOU CANNOT INSURE 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 THE DISABLED INFANT...GROWING CHILD...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. IN MANY CASES, THOSE PERCEPTIONS MAY BE WRONG.

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 SERVICE TO DISABLED CHILDREN AND THEIR PARENTS, EACH SERVICE 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 WILL THEN BE MORE LIKELY TO RECOGNIZE AND 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 LUNCHEON SPEAKERS, I TOO MAY HAVE OVERSIMPLIFIED THE MATTER. SO LET ME CORRECT THAT IMPRESSION.

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 THEY 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 -- A CATEGORY CREATED BY 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.

WE 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. FOR THOSE CHILDREN AND THEIR FAMILIES, OTHER KINDS OF SERVICES WOULD HAVE 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, 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 LAYPERSONS TO OPERATE, AND IT SHOULD BE MORE 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 HAS 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 CONFERENCE PROGRAM. THEREFORE, I WILL CLOSE THIS MESSAGE TO YOU WITH A LITTLE STORY OF A PERSONAL EXPERIENCE I HAD NOT LONG AGO.

I HAD BEEN INVITED TO LECTURE AT THE UNIVERSITY OF TORONTO ON THE SURGEON'S ROLE IN THE CARE OF THE DISABLED NEWBORN. WHILE PREPARING MY NOTES, I CONSULTED WITH THE MOTHER OF A 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 WORST THING THAT HAS EVER HAPPENED TO YOU IN YOUR LIFE?"

SHE ANSWERED, "HAVING OUR SON, WHO WAS 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 TWO 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 BEST THING THAT EVER HAPPENED IN YOUR LIFE?"

AND SHE ANSWERED, "HAVING OUR SON, WHO WAS 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.

#