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TOTAL CARE FOR THE DISABLED CHILD

BY

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KEYNOTE ADDRESS TO THE FIRST INTERNATIONAL CONFERENCE ON

PEDIATRIC SOCIAL WORK

CHICAGO, ILLINOIS

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(GREETINGS TO HOSTS, SPECIAL GUESTS, ETC.)

YOU HAVE ACCORDED ME A HIGH HONOR BY INVITING ME TO SHARE MY THOUGHTS WITH YOU AT THIS FIRST INTERNATIONAL CONFERENCE ON PEDIATRIC SOCIAL WORK. I HAVE SPENT MY ENTIRE ADULT LIFE IN PEDIATRIC SURGERY. AND IF I HAD IT TO DO ALL OVER AGAIN -- I GLADLY WOULD. THE ONLY THING I WOULD CHANGE IS MY OVERALL GOAL: I WOULD WANT TO DO EVERYTHING I HAD ALREADY DONE, BUT I WOULD WANT TO DO IT BETTER.

MY PATIENTS HAVE BEEN AMONG THE MOST VULNERABLE OF HUMAN BEINGS... CHILDREN WHO WERE EXPERIENCING A SEVERE PHYSICAL DISABILITY, A LIFE-THREATENING DISABILITY, BUT WHO NEVERTHELESS COULD NOT TELL US ABOUT IT. IN SUCH SITUATIONS, HUMAN LANGUAGE -- OUR MOST EFFECTIVE MEDIUM FOR GIVING REASSURANCE -- IS OF LITTLE OR NO USE. THESE PATIENTS ARE, FOR ALL INTENTS AND PURPOSES, INCOMMUNICADO.

YET, IT HAS BEEN MY EXPERIENCE, DURING THESE PERIODS OF TREATMENT AND CARE, TO BE JOINED BY TRAINED, COMPASSIONATE SOCIAL SERVICE PROFESSIONALS. I HAVE OBSERVED THEM GIVE OUR TINY PATIENTS A PRICELESS MOMENT OR TWO OF COMFORT, AS WELL AS PROVIDE THE PARENTS AND SIBLINGS WITH A MEASURE OF CHARITY AND UNDERSTANDING. WHAT THEY DO IS TO GIVE BOTH THE FAMILY AND THE HOSPITAL STAFF THE STRENGTH TO KEEP GOING.

SO IT IS WITH A DEEP SENSE OF BEING AMONG GOOD FRIENDS THAT I JOIN YOU THIS EVENING TO TALK ABOUT SOME ISSUES THAT NEED TO BE ADDRESSED BY BOTH THE MEDICAL AND THE SOCIAL SERVICES COMMUNITIES. I WANT TO CONGRATULATE DR. JOHNSON AND HIS STAFF FOR THE OVERALL CONCEPTION OF THIS CONFERENCE AND FOR BRINGING TOGETHER SUCH AN OUTSTANDING CONFERENCE FACULTY.

FIRST, LET ME SAY THAT I AM SINCERELY IMPRESSED BY THE EXTRAORDINARY RANGE OF ISSUES THAT CONCERN YOU DURING THESE FOUR DAYS. MANY OF THESE ISSUES HAVE LONG HISTORIES. THEY HAVE BEEN MANKIND'S CONSTANT COMPANIONS THROUGHOUT OUR JOURNEY ON THIS PLANET:

- \* THE FREQUENT AMBIGUITY OF THE PARENT-CHILD RELATIONSHIP,
- \* OUR EFFORTS TO SOMEHOW GIVE HUMAN LIFE A SPECIFIC VALUE,
- \* THE RELIABILITY OF LOVE AS A PRIMARY MOTIVATION,
- \* CHARITY'S VULNERABILITY TO DISGUISE,
- \* AND OUR STUBBORN INNOCENCE IN DEALING WITH OUR OWN MORTALITY.

THESE AND OTHERS ARE NOT SIMPLE ISSUES. THEY DON'T INVITE SIMPLE ANSWERS. RATHER, THEY CHALLENGE US ON THE MOST PROFOUND LEVELS OF OUR EXISTENCE. AND IT MAY WELL BE THAT THE SINGLE BEST WAY TO MEASURE JUST HOW "CIVILIZED" MANKIND HAS BECOME IS TO SEE THE EXTENT TO WHICH WE CAN ADMIT THAT THESE ISSUES EXIST AND, ONCE HAVING DONE THAT, TO GO FORWARD AND DEMONSTRATE THE WILL AND THE WIT TO DO SOMETHING ABOUT THEM.

THIS WEEK, HERE IN CHICAGO, YOU ARE ALL MEASURING UP VERY WELL.

AND THAT MAKES MY JOB ALL THE MORE DIFFICULT. BUT, WITH YOUR INDULGENCE, LET ME SPEND THE NEXT FEW MINUTES SHARING WITH YOU SOME INFORMATION THAT HAS COLORED MY OWN PERCEPTIONS IN THIS AREA, SOME PERSONAL EXPERIENCES, AND SOME OBSERVATIONS ON ROLES -- SPECIFICALLY THE ROLE OF MEDICINE AND THE ROLE OF SOCIAL SERVICE.

FIRST, I THINK WE ALL NEED TO REMEMBER THAT, AS DIFFICULT AS OUR OWN PARTICULAR TASKS MAY SOMETIMES BE AND AS SERIOUS AS SOME OF THE SPECIFIC PROBLEMS MAY BE FOR OUR PATIENTS AND THEIR FAMILIES, THE OVERWHELMING DIRECTION OF INFANT AND CHILD HEALTH IN THIS COUNTRY IS TOWARD IMPROVED CARE AND BETTER OUTCOMES. THE INFANT MORTALITY RATE

IS STILL DECLINING: THE APRIL PROVISIONAL RATE, THE LATEST FIGURE WE HAVE, STANDS AT 11.5 DEATHS PER 1,000 LIVE BIRTHS. THERE HAD BEEN SOME FEELING IN THE PAST YEAR OR SO THAT WE WERE HITTING A PLATEAU, THAT THE CURVE WOULD BEGIN TO FLATTEN OUT AND WE WOULD HAVE TO BEGIN DEALING WITH THE HARD-CORE ISSUES AFFECTING PERINATAL CARE IN THIS COUNTRY. BUT THE CURVE IS NOT FLATTENING OUT. IT IS STILL GOING DOWN AT ABOUT THE SAME ANGLE.

WE ARE APPARENTLY DOING SOME THINGS RIGHT, ALTHOUGH IT IS NEARLY IMPOSSIBLE TO IDENTIFY WHICH SPECIFIC "THINGS" ACCOUNT FOR WHAT PORTION OF OUR SUCCESS. HENCE, SETTING PRIORITIES IS VERY DIFFICULT. IN ADDITION, IT SEEMS CLEAR THAT MOST OF THE INFANT LIVES WE ARE SAVING ARE HEALTHY LIVES. THERE IS NO REAL EVIDENCE SO FAR THAT THE INFANT MORBIDITY RATE IS RISING AS THE INFANT MORTALITY RATE GOES DOWN. BUT, IN ALL CANDOR, WE HAVE NOT DONE THE KIND OF RESEARCH THAT'S REQUIRED IN ORDER TO ELEVATE THIS CONCLUSION ABOVE THE LEVEL OF WHAT IT REALLY IS: AN INSTINCTIVE, VISCERAL RESPONSE BY PEOPLE IN THE FIELD OF PERINATOLOGY.

BUT IT'S NOT NECESSARY TO HAVE STATISTICAL CURVES GO SHARPLY UP OR DOWN TO UNDERSTAND THE IMPACT A DISABLED INFANT HAS UPON ITS PARENTS AND THE ATTENDING MEDICAL AND SOCIAL SERVICES STAFFS. NOR DO WE NEED A GREAT DEAL OF DOCUMENTATION TO KNOW THAT A DISABLED NEONATE EXACTS A HIGH COST IN BOTH EMOTIONAL AND MONETARY TERMS. GIVING BIRTH IS A HIGHLY COMPLEX EMOTIONAL, PSYCHOLOGICAL, AND PHYSICAL EVENT EVEN WHEN A HEALTHY BABY IS DELIVERED. HOW MUCH MORE COMPLEX IT CAN BE WHEN THE INFANT IS DISABLED. ALL THE PERSONS INVOLVED -- PARENTS AND HOSPITAL STAFF -- SHARE THE FEELINGS OF GUILT AND INADEQUACY.

BUT ULTIMATELY IT IS THE INFANT ITSELF WHO NEEDS THE UNDERSTANDING AND THE AFFECTION AND THE CARE IN ORDER FOR IT TO HAVE A CHANCE AT LIFE. AND HE OR SHE WILL GET IT, PROVIDING THE GROUNDWORK HAS BEEN LAID THROUGH THE DEVELOPMENT OF A HUMAN CLOSENESS BETWEEN PARENTS AND PHYSICIAN. SOMETIMES THIS CAN BE CARRIED OUT BY THE PHYSICIAN; MUCH DEPENDS ON TRAINING, PERSONAL COMMITMENT, WORKLOAD, AND OTHER FACTORS. WHERE THIS KIND OF RELATIONSHIP IS NOT DEVELOPING, THE ASSISTANCE OF SOCIAL SERVICE STAFF WOULD BE ESSENTIAL.

THE OVERWHELMING NUMBER OF PARENTS OF HANDICAPPED NEWBORNS -- OVER 95 PERCENT -- TAKE RESPONSIBILITY FOR THEIR CHILDREN, TAKE THEM HOME, AND TRY TO ABSORB THEM INTO THEIR FAMILY LIFE. OUR CHALLENGE IS TO HELP THOSE PARENTS UNDERSTAND, LOVE, AND HELP THEIR CHILD. MEDICINE AND SOCIAL SERVICE CANNOT TAKE THE PLACE OF THE FAMILY. RATHER, THEY SHOULD USE THEIR TALENTS AND EXPERTISE 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 HELP 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 ASPECTS OF THE BEST POSSIBLE QUALITY OF LIFE FOR THE DISABLED CHILD.

BUT THE CHANCE TO HELP PARENTS BECOME A FAMILY IS POSSIBLE ONLY IF THE PARENTS ARE CAPABLE AND WANT IT TO HAPPEN. SOME AREN'T...AND DON'T. A VERY SMALL PERCENTAGE OF OUR ADULT POPULATION IS NOT EMOTIONALLY OR MENTALLY COMPETENT AND, THEY THEMSELVES, REQUIRE SOCIETY'S ATTENTION. SOME OF THEM BEAR CHILDREN AND IMMEDIATELY SURRENDER THEIR INFANTS, EITHER VOLUNTARILY OR INVOLUNTARILY. SOME PARENTS ABANDON

THEIR CHILDREN AS SOON AS POSSIBLE. AND SOME KEEP THEM -- BUT NOT FOR VERY LONG. THIS LAST GROUP NEEDS MUCH MORE OF OUR ATTENTION.

AT THIS TIME WE DO NOT HAVE A CLEAR IDEA OF THE NUMBERS OF MOTHERS WHO TAKE HOME INFANTS BORN WITH ONE OR MULTIPLE DISABILITIES, WHO TRY TO ABSORB THE INFORMATION ABOUT THE CARE THEY NEED, WHO MAKE AN ATTEMPT AT COPING WITH ALL THE ATTENDANT PROBLEMS -- BUT WHO ULTIMATELY DECIDE TO SURRENDER THEIR CHILDREN FOR ADOPTION OR INSTITUTIONALIZATION. IT HAS BEEN MY EXPERIENCE THAT MANY OF THESE DECISION WERE MADE BY PARENTS WHO WOULD HAVE BEEN REWARDED A HUNDRED-FOLD BY THEIR CHILD, IF THEY HAD ONLY HELD ON FOR JUST A LITTLE LONGER AND HAD BEEN GIVEN JUST A LITTLE ADDITIONAL SUPPORT. AND THE CHILD, IN THE OVERWHELMING NUMBER OF SUCH CASES, WOULD ALSO HAVE HAD A CHANCE AT A MORE FULFILLED AND FULFILLING LIFE. WHAT WENT WRONG? CAN WE DO ANYTHING ABOUT IT?

I THINK THERE ARE SOME THINGS WE CAN DO THAT -- AGAIN FROM PERSONAL EXPERIENCE -- I KNOW WILL WORK. THESE ARE TASKS THAT CUT ACROSS DISCIPLINES AND I OFFER THEM TO THIS AUDIENCE BECAUSE OF THE SCOPE OF INTERESTS AND SKILLS YOU REPRESENT.

THE FIRST TASK, IT SEEMS TO ME, WOULD BE TO PREPARE THE <sup>pediatric</sup> ~~OBSTETRIC~~ MEDICAL STAFF FOR POSSIBLE LONG-TERM RELATIONSHIPS WITH SOME PARENTS. MOST DELIVERIES IN THIS COUNTRY ARE TROUBLE-FREE AND MOST INFANTS ARE HEALTHY. HENCE, IT IS UNDERSTANDABLE WHEN MEDICAL STAFFS ARE COURTEOUS AND CHEERFUL -- ALMOST BREEZY AT TIMES -- AND QUITE SKILLED AT KEEPING THEIR PATIENT RELATIONS BRIEF AND SUPERFICIAL. AND, TO BE FAIR, I THINK MOST PATIENTS WOULD JUST AS SOON HAVE IT THIS WAY, TOO. PARENTS USUALLY TAKE THEIR BABIES HOME WITH THE STRONG WISH THAT THE CHILD MAY NEVER HAVE TO SET FOOT IN THAT OR ANY OTHER HOSPITAL EVER AGAIN. AND I WOULD BE THE FIRST ONE TO SAY "AMEN" TO THAT.

BUT THEN THERE IS THE INFANT BORN WITH DOWN'S SYNDROME, THE SPINA BIFIDA BABY, THE CHILD WITH SOME CONGENITAL DEFECT -- A DAMAGED ORGAN SYSTEM, A MISSING OR DEFORMED LIMB -- OR ONE OF ANY NUMBER OF OTHER DISABLING CONDITIONS. THE PEOPLE TO WHOM THE PARENTS TURN TO FIRST ARE THE MEDICAL STAFF. 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 SHOULD HAVE DONE SOMETHING AND DIDN'T?

AT THAT POINT, THE PHYSICIAN-PATIENT RELATIONSHIP IS NO LONGER CASUAL. NOR WILL IT BE SHORT-TERM. THE PHYSICIAN HAS TO TRANSLATE WHAT MIGHT BE COMPLICATED MEDICAL TERMINOLOGY INTO WORDS THE PARENTS CAN UNDERSTAND -- AND NOT FEAR. THE FIRST MEETING WITH PARENTS SHOULD BE FOCUSED ENTIRELY ON DESCRIBING THE INFANT'S PARTICULAR PROBLEM. THEY NEED TO UNDERSTAND THIS AS COMPLETELY AS POSSIBLE, IN ORDER TO RATIONALLY TACKLE FAMILY, FINANCIAL, EMOTIONAL, AND OTHER ISSUES LATER ON. THEN THEY NEED SOME TIME TO THEMSELVES, BEFORE THE PHYSICIAN COMES BACK TO ANSWER OTHER QUESTIONS AND THEN BEGIN TO HELP THEM FACE THE FUTURE.

ONE BASIC RULE NEEDS TO BE OBSERVED AT THIS TIME: NO MATTER HOW SERIOUS THE INFANT'S CONDITION IS AND NO MATTER HOW IT MAY AFFECT THE PHYSICIAN, IT IS ESSENTIAL THAT THE PHYSICIAN NOT TRANSMIT IN ANY WAY A SENSE OF HOPELESSNESS OR FUTILITY OR, IN EFFECT, GO INTO MOURNING FOR A CHILD WHO IS STILL IS VERY MUCH ALIVE, HOWEVER SEVERE ITS PHYSICAL OR MENTAL BURDEN.

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 SPEAKING IN TERMS OF 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. BUT WE NEED TO BUILD ON THEIR STRENGTHS. AND, AS I MENTIONED A MOMENT AGO, EXCEPT FOR A VERY SMALL PERCENTAGE OF AMERICANS WHO EXHIBIT CERTAIN PERSONAL AND SOCIAL INADEQUACIES, WE DO HAVE THE STRENGTHS TO CARRY US THROUGH SOME PRETTY DIFFICULT HUMAN TRAUMA.

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, COMPASSIONATE, HIGHLY PERSONAL, AND POSSIBLY PROLONGED RELATIONSHIP WITH PARENTS WHO MAY BE SETTING OUT ON A LONG AND INTRICATE JOURNEY IN HUMAN GROWTH.

YOUNG PHYSICIANS ESPECIALLY NEED THIS KIND OF TRAINING. 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 NORMAL STATE. BUT MANY DISABLED NEONATES CANNOT BE "CURED" OR READILY "REPAIRED." THEY MAY NEVER APPROACH WHAT MIGHT BE CONSIDERED A "NORMAL" STATE OF FUNCTIONING AT ANY TIME IN THEIR LIVES -- AND THEIR VERY LIVES MAY BE BRIEF.

A SECOND AND COMPLEMENTARY TASK IS TO EXPAND AND STRENGTHEN THE FACILITATING SKILLS OF THE SOCIAL SERVICES STAFF. I SPOKE RATHER CASUALLY ABOUT THE MEETINGS BETWEEN ATTENDING PHYSICIAN AND PARENTS. BUT THESE ARE NOT CASUAL EVENTS. THEY NEED TO MEET IN PRIVACY AND IN A SETTING THAT IS NOT MEDICALLY OR SOCIALLY INTIMIDATING. THE TIMING MUST BE SUCH THAT BOTH PARENTS ARE AVAILABLE AND NOT PRESSED BY ANY OTHER APPOINTMENTS. THE PHYSICIAN MUST ALSO BE AVAILABLE AND HAVE ENOUGH TIME TO WORK THROUGH ANY ESPECIALLY SENSITIVE INFORMATION.

MOST PEOPLE MAY BE AWARE OF CERTAIN SOCIAL SERVICE OR HEALTH AGENCIES OR MAY EVEN HAVE BEEN REGULAR CONTRIBUTORS TO CERTAIN

VOLUNTARY ORGANIZATIONS CONCERNED WITH ONE OR ANOTHER DISEASE OR DISABILITY. BUT WHEN FACED BY THE IMMEDIATE NEED TO GET INFORMATION, APPLY FOR HELP, REQUEST CERTAIN RESOURCES, MAKE CONNECTIONS, MAKE DECISIONS -- MUCH OF THEIR PAST EXPERIENCE AND KNOWLEDGE BECOMES SOMEHOW DISJUNCTIVE. EVEN IF THEY HAVE MADE A COMMITMENT TO CARE FOR THEIR CHILD AND GIVE IT ALL THE LOVE IT NEEDS, THEY MAY BE OVERWHELMED BY THE BYZANTINE COMPLEXITY OF OUR SOCIAL SERVICE DELIVERY SYSTEM. SOCIETY MAY CONSPIRE AGAINST THEIR HUMANITY.

IN MY PREVIOUS ROLE AS A PEDIATRIC SURGEON, I FREQUENTLY WAS THE PERSON WHO WORKED SIDE-BY-SIDE WITH PARENTS, NEGOTIATING HELP FROM A WIDE NETWORK OF PRIVATE, PUBLIC, FREE, AND FEE-FOR-SERVICE PROVIDERS. IT IS NOT A SURGEON'S ROLE. WE'RE JUST NOT VERY GOOD AT IT. WE DON'T KNOW ALL THAT MUCH ABOUT WHAT'S AVAILABLE. BUT IT WAS BETTER THAN NO HELP AT ALL. IT'S ONLY FAIR TO ADD, HOWEVER, THAT THESE OCCASIONS WERE USUALLY OF MY OWN CHOOSING, BASED UPON A CLOSENESS THAT MAY HAVE DEVELOPED AMONG ME, MY PATIENT, AND ITS PARENTS. THE SOCIAL SERVICES STAFF AT THE CHILDREN'S HOSPITAL OF PHILADELPHIA WAS -- AND STILL IS -- JUST FIRST-RATE.

I USED THE TERM "FACILITATING" BECAUSE I THINK THE ROLE OF 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 HAVE RICH AND VARIED BIOGRAPHIES, JUST AS INDIVIDUAL PEOPLE DO. FORTUNES RISE AND FALL. CHILDREN DO OR DO NOT ALL GET ALONG WITH EACH OTHER. MOTHERS MAY OR MAY NOT SUCCEED IN DEVELOPING A STRONG BOND WITH THEIR DISABLED INFANT. HUSBANDS AND WIVES MAY OR MAY NOT CLEAVE TO EACH OTHER TILL DEATH DOES THEM PART. AND THE DISABLED INFANT...GROWING CHILD...YOUNG ADULT...AND ADULT ARE PART OF THAT EVOLUTION, THAT MIRACLE OF HUMAN GROWTH.

THIS IS AN IMPORTANT POINT, SINCE SOCIAL SERVICE WORKERS, SPECIAL EDUCATION PERSONNEL, AND OTHERS WHO DELIVER THESE VITAL HUMAN SERVICES, ARE VULNERABLE TO THE "BURN-OUT" SYNDROME. THAT IS A TERRIBLE LOSS -- BOTH PERSONAL AND PROFESSIONAL.

I DON'T PRETEND TO KNOW WHERE THE DIVIDING LINE IS. MAYBE THERE JUST ISN'T ONE TO SHOW; 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 ARE MORE LIKELY TO RECOGNIZE AND APPRECIATE MINE.

A THIRD TASK FOR US ALL, AND THE LAST ONE I WANT TO DWELL ON TODAY, IS THE NEED TO CONTROL -- RATHER BE CONTROLLED BY -- THE NEW TECHNOLOGY OF MEDICINE AND HEALTH CARE. ONE OF THE MOST CURRENT AND, I WOULD ADD, THE MOST DRAMATIC EXAMPLES IN THE FIELD OF NEONATOLOGY, CONCERNS THE PROBLEM OF THE RESPIRATOR-DEPENDENT CHILD.

EARLIER ON, I MENTIONED THE FACT THAT THE INFANT MORTALITY RATE WAS DECLINING AND THAT, AS NEAR AS WE COULD TELL, MOST OF THE BABIES WERE ARE SAVING ARE HEALTHY BABIES. THE MORBIDITY RATE IS NOT TURNING SHARPLY UP. LIKE A LOT OF PEOPLE WHO GIVE KEYNOTE SPEECHES, I TOO MAY HAVE OVERSIMPLIFIED TO MAKE MY EARLIER POINT. SO LET ME CORRECT THAT IMPRESSION WITH THIS EXAMPLE.

A NUMBER OF THE INFANTS WE ARE SAVING ARE PREMATURE OR LOW BIRTH WEIGHT OR IMMATURE IN SOME ASPECT OF THEIR DEVELOPMENT. THEY MAY BE IMMEDIATELY TAKEN TO AN INFANT INTENSIVE CARE UNIT, IF THERE IS ONE AVAILABLE WITH A WAITING BASSINETTE, AND PUT ON RESPIRATOR THERAPY UNTIL THEY ACHIEVE NORMAL WEIGHT AND LEVEL OF DEVELOPMENT. THESE BABIES ARE USUALLY THE ONES THAT MIGHT NOT HAVE SURVIVED THEIR BIRTH NOT TOO LONG AGO. BUT TODAY THEY ARE ALIVE. BUT THEY REPRESENT A NEW CATEGORY OF DISABLED CHILD -- A CATEGORY CREATED BY THE I.I.C.U. TECHNOLOGY.

AT PHILADELPHIA CHILDREN'S, WHEN WE WERE DEVELOPING THIS LIFE-SAVING TECHNOLOGY, THE COST OF THIS IN-PATIENT THERAPY WAS ABOUT \$1,000 PER DAY PER RESPIRATOR-DEPENDENT CHILD. IN A 12-MONTH PERIOD, FROM 1980 TO 1981, THERE WERE 235 SUCH CHILDREN IN THE COMMONWEALTH OF PENNSYLVANIA. A CHILD WAS "DEPENDENT" IF IT HAD TO BE ON THE RESPIRATOR FOR NOT LESS THAN 4 HOURS A DAY FOR 30 DAYS OR MORE IN THAT CALENDAR YEAR. A LITTLE SIMPLE ARITHMETIC TELLS YOU THAT THE MINIMUM COST FOR THE CARE OF THESE CHILDREN THAT YEAR HAD TO BE NOT LESS THAN \$7,000,000 MILLION FOR THE CARE OF RESPIRATOR-DEPENDENT CHILDREN WHO FIT THE SURVEY'S MINIMUM DEFINITION.

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

WE LOOKED INTO THE SITUATION AND WE DISCOVERED THAT THE TECHNOLOGY ALREADY EXISTED -- AND IT COULD BE FURTHER REFINED -- TO PROVIDE THE RESPIRATOR SUPPORT FOR SUCH CHILDREN IN THEIR OWN HOMES. THE COST IS ESTIMATED TO BE ABOUT \$200 A WEEK. THEORETICALLY, THEN, IF THOSE SAME 235 CHILDREN, THE ONES WHO MET THE SURVEY'S MINIMUM DEFINITION, WERE ALL ALLOWED TO GO HOME, THE COST FOR RESPIRATOR SUPPORT WOULD BE ONLY \$188,000.

NATURALLY, THEY ALL COULD NOT GO HOME. AND FOR THOSE WHO DID, OTHER KINDS OF SERVICES WOULD HAVE TO BE PROVIDED IN THEIR HOMES, SERVICES SUCH AS PHYSIOTHERAPY, OCCUPATIONAL THERAPY, SOME SPECIFIC NURSING CARE, AND SPECIAL EDUCATIONAL SERVICES. BUT EVEN ADDING THESE TO OUR THEORETICAL TOTAL, WE STILL ARRIVE AT A HOME-CARE COST THAT IS SIGNIFICANTLY LESS THAN \$7,000,000.

THE SAVINGS ARE NOT JUST IN DOLLARS. THERE ARE ALSO THE HUMAN SAVINGS, A POSSIBLE REDUCTION IN THE ENORMOUS EMOTIONAL AND PSYCHOLOGICAL BURDENS CARRIED BY THE CHILD AND ITS FAMILY. AND 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.

I BELIEVE WE HAVE TO SET SOME OF OUR OWN DEMANDS FOR THE IMPROVEMENT OF THIS NEW RESPIRATOR TECHNOLOGY. FOR EXAMPLE, IT HAS TO BE REDUCED IN SIZE WITHOUT DIMINISHING ITS EFFECTIVENESS. IT HAS TO BE SIMPLE ENOUGH TO OPERATE SO THAT UNTRAINED LAYPERSONS -- THE AVERAGE PARENT OR SIBLING -- CAN OPERATE IT WITHOUT ENDANGERING THE CHILD. IT HAS TO BE PORTABLE AND FLEXIBLE ENOUGH TO ADJUST TO DIFFERENT KINDS OF LIVING ARRANGEMENTS. NONE OF THESE CONDITIONS ARE IMPOSSIBLE TO MEET.

BUT WE ALSO HAVE TO LOOK AT OUR MEDICAL AND SOCIAL SERVICES PERSONNEL. WE NEED TO MAKE SURE THEY UNDERSTAND THAT THE MOVEMENT OF THE CHILD OUT OF THE HOSPITAL AND INTO THE HOME SHOULD BE ACCOMPLISHED AS SOON AS POSSIBLE. THEY NEED TO PREPARE THE FAMILY FOR THAT EVENT.

THEY MAY NEED TO WORK WITH INSURERS, THIRD-PARTY PAYORS, OR VOLUNTARY AGENCIES TO HELP THE TRANSFER TAKE PLACE. THEY NEED TO OPEN LINES OF EMERGENCY COMMUNICATION FOR PARENTS TO USE -- OR AT LEAST TO KNOW ARE THERE. IN OTHER WORDS, THEY HAVE TO TAKE SERIOUSLY THIS NEW OUTPATIENT OPTION AND CONVEY THEIR BELIEF IN IT TO THE PARENTS OF THEIR RESPIRATOR-DEPENDENT PATIENTS.

WE ARE LOOKING AT THIS IMPORTANT DEVELOPMENT FROM THE POINT OF VIEW OF THE GOVERNMENT'S REIMBURSEMENT PROGRAMS. AS YOU MAY RECALL, THE GOVERNMENT HAD IN PLACE REGULATIONS THAT PREVENTED LITTLE KATIE BECKETT FROM RETURNING TO HER PARENTS' HOME IN IOWA BECAUSE, IN DOING SO, SHE WOULD HAVE LOST HER MEDICAID ELIGIBILITY. IN OTHER WORDS, BEING SENT HOME WAS A FORM OF PUNISHMENT.

IT MADE NO SENSE.

SECRETARY RICHARD SCHWEIKER, WHEN INFORMED OF THIS CASE, STEPPED IN AND PERMITTED KATIE TO GO HOME AND HER FAMILY TO CONTINUE RECEIVING SUPPORT. IT WAS AN EXTRAORDINARY ACTION AND NOT THE WAY TO RUN THE GOVERNMENT ON A DAY-TO-DAY BASIS. THE DEPARTMENT OF HEALTH AND HUMAN

SERVICES, AT SECRETARY SCHWEIKER'S DIRECTION, NOW HAS A BOARD OF REVIEW AND A NEW SET OF REGULATIONS THAT ALLOWS THE KATIE BECKETTS OF THIS COUNTRY TO GET THE HOME CARE THEY SHOULD HAVE AND STILL RECEIVE THE GOVERNMENT ASSISTANCE FOR WHICH THEY ARE ELIGIBLE.

WE AREN'T GOING TO MOVE ALL OUR RESPIRATOR-DEPENDENT CHILDREN OUT OF INTENSIVE CARE WITH THE HELP OF THIS BOARD. SOME CHILDREN WITH PROGRESSIVE NEUROMUSCULAR DISABILITIES MUST BE KEPT ON THE EQUIPMENT FOR THE REST OF WHAT MAY BE A BRIEF LIFE. OTHER CHILDREN WITH CERTAIN CONGENITAL ANOMALIES THAT JUST TAKE A LITTLE TIME TO SELF-CORRECT OR BE SURGICALLY CORRECTED CAN COME OFF THE HOSPITAL EQUIPMENT AND MAY HAVE THE CHANCE TO GO HOME MUCH SOONER THAN WE HAD ONCE THOUGHT POSSIBLE. AND STILL OTHERS, QUADRIPLAGIC CHILDREN, NOT NEONATES BUT OLDER CHILDREN WHO HAVE BEEN IN AUTO ACCIDENTS OR HAVE SUFFERED OTHER TRAUMA, SEEM TO BE THE MOST STABLE AND MAY BE SENT BACK TO THE CARE OF THEIR FAMILIES MUCH SOONER.

THESE ARE DECISIONS THAT ARE JUST NOW BEING MADE BY MEDICAL AND SOCIAL SERVICES STAFFS IN THOSE HOSPITALS WHERE THIS KIND OF THERAPY IS EVOLVING. LATER THIS YEAR, WE PLAN TO HOLD A SURGEON GENERAL'S CONFERENCE ON THE DISABLED CHILD AND CERTAINLY ONE OF THE MAIN TOPICS ON THE AGENDA WILL BE THE FUTURE OF RESPIRATOR THERAPY IN THE FAMILY SETTING. SO I AM HOPEFUL OF MUCH PROGRESS IN THIS AREA. I ALSO HOPE THAT THESE KINDS OF EXPERIENCES WILL GRADUALLY GIVE US THE ABILITY TO CONTROL AND DIRECT THE FUTURE OF MUCH OF OUR MEDICAL TECHNOLOGY SO THAT IT REMAINS OUR SERVANT AND NOT OUR MASTER.

I'VE HAD MORE THAN MY SHARE OF TIME AT THE PODIUM, FOR WHICH I AM GRATEFUL. BUT TO BE HONEST WITH YOU, I COULD STAY HERE AND CONTINUE TO SPEAK OF THE GREAT NEED FOR THE KIND OF WORK YOU DO NOT ONLY WITH INFANTS BUT WITH CHILDREN OF ALL AGES AND WITH ALL DISEASE AND DISABLING CONDITIONS. IT IS PROFOUNDLY IMPORTANT FOR OUR SOCIETY THAT WE TEND TO THESE ISSUES, THAT THESE CHILDREN NOT BE FORGOTTEN OR PUSHED ASIDE, AND THAT WE RETAIN OUR BELIEF IN THE STRENGTH OF THE AMERICAN FAMILY TO ABSORB WHATEVER LIFE HAS TO OFFER.

IN THIS CONNECTION, I WANT TO CLOSE WITH A LITTLE STORY OF A PERSONAL EXPERIENCE I HAD NOT LONG AGO. I HAD BEEN INVITED TO GIVE A

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 OPERATIONS. BUT I ALSO KNOW THAT SHE HAS A STRONG FAMILY, A DEVOTED HUSBAND, AND TWO OTHER CHILDREN WHO WERE BORN HEALTHY AND HAVE BEEN LOVING SIBLINGS TO HER SON. THEN 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."

IN CASE I HAD FORGOTTEN, THIS WONDERFUL WOMAN REMINDED ME 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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