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KEYNOTE

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AND

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PRESENTED TO THE SURGEON GENERAL'S CONFERENCE ON
CHILDREN WITH HANDICAPS AND THEIR FAMILIES
PHILADELPHIA, PENNSYLVANIA
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(GREETINGS TO HOSTS, GUESTS)

I WANT TO THANK EVERYONE WHO HAS CONTRIBUTED TO THIS WORKSHOP IN ANY CAPACITY AT ALL. THE SUBJECT IS ONE OF GREAT NATIONAL CONCERN AND THE ATTENDANCE LIST IS JUST SHIMMERING WITH THE NAMES OF PEOPLE KNOWN FOR THEIR KNOWLEDGE, EXPERIENCE, AND -- MOST IMPORTANT OF ALL -- THEIR HUMANENESS.

I CAN TELL YOU FROM PERSONAL EXPERIENCE THAT IT'S DIFFICULT FOR SOMEONE TO GET INTO THE GOVERNMENT. BUT EVEN ONCE YOU'RE INSIDE, IT'S AWFULLY HARD TO GET THINGS DONE. MAYBE THAT'S GOOD...MAYBE THAT PROTECTS ALL OF US FROM HAVING A GOVERNMENT THAT KNOWS TOO MUCH ABOUT US AND WANTS TO DO TOO MUCH FOR US. ON THE OTHER HAND, IT MEANS THAT THE CONTRIBUTION OF EVERY SINGLE PERSON IN A GOVERNMENT-SPONSORED EVENT SUCH AS THIS WORKSHOP IS ESPECIALLY IMPORTANT AND APPRECIATED. SO...THANK YOU ONCE AGAIN.

OUR TASK TODAY AND TOMORROW IS NOT AN EASY ONE. WE ARE ASKING EACH OTHER TO DEAL WITH A VERY COMPLEX ISSUE AND TO DO SO, KEEPING IN MIND THE MANY LEVELS OF COMPLEXITY: THE <u>EMOTIONAL</u> AND THE <u>MORAL</u>, THE <u>MEDICAL</u> AND THE <u>TECHNOLOGICAL</u>, THE <u>SOCIAL</u>, THE <u>PSYCHOLOGICAL</u>, AND THE <u>FINANCIAL</u>.

OF COURSE, WE WON'T ALWAYS BE EXPLICITLY ATTENDING TO EACH OF THESE LEVELS. BUT WE KNOW THEY ARE THERE. WHEN WE TALK ABOUT "COST-EFFECTIVE LIFE-SUPPORT SYSTEMS," WE ARE <u>IM</u>PLICITLY PUTTING SOME DOLLAR VALUE ON A HUMAN LIFE. WE MAY NOT WANT TO ADMIT IT, BUT THAT'S CERTAINLY ONE OUTCOME. SO THE MORAL AND THE TECHNOLOGICAL AND THE ECONOMIC DO COME TOGETHER, WHETHER OR NOT WE FEEL COMFORTABLE ABOUT IT.

THERE IS YET ANOTHER COMPLICATION. THE LIVES WE ARE CONCERNED WITH AT THIS WORKSHOP ARE NEW LIVES. WE ARE ABLE TO INTERACT WITH THEM, BUT THERE IS A CLEAR LIMIT TO THIS INTERACTION. WE KNOW, FOR EXAMPLE, THAT THERE CAN BE NO TRUE "INFORMED CONSENT" WITH A NEWBORN -- PARTICULARLY IF THE NEWBORN IS DISABLED IN SOME WAY. SO WE MUST TURN TO THE PARENTS OF THOSE NEW LIVES FOR UNDERSTANDING AND CONSENT.

AND WE MUST ALSO TURN BACK TO OUR OWN KNOWLEDGE AND EXPERIENCE AND HUMAN UNDERSTANDING, FOR WE PROFESSIONALS IN HEALTH AND SOCIAL SERVICES MUST FIRST OBTAIN FROM <u>OURSELVES</u> OUR <u>OWN</u> "INFORMED CONSENT" BEFORE GOING AHEAD WITH ANY PROCEDURE OR BEFORE OFFERING ANY ADVICE. PATIENTS AND FAMILIES MAY COME AND GO, BUT WE HAVE OURSELVES TO FACE IN THE MIRROR EVERY MORNING.

I HAVE SPENT MY ENTIRE ADULT LIFE IN PEDIATRIC SURGERY. AND IF I HAD IT TO DO ALL OVER AGAIN -- I GLADLY WOULD. MY PATIENTS WERE 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, <u>INCOMMUNICADO</u>. UNABLE TO GET THEIR "INFORMED CONSENT," I SCRUPULOUSLY ASKED FOR THE CONSENT OF THEIR PARENTS OR GUARDIANS. AND I WANTED MY OWN AS WELL.

BUT IT WOULD BE A MISTAKE FOR ME TO DWELL ON THE POTENTIAL HURDLES AND BARRIERS TO THE CARE OF DISABLED INFANTS AND CHILDREN. 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 PROVISIONAL RATE FOR THE 12 MONTHS ENDING IN JULY, THE LATEST FIGURE WE HAVE, STANDS AT 11.3 INFANT DEATHS PER 1,000 LIVE BIRTHS, THE LOWEST 12-MONTH RATE IN

OUR HISTORY. 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 <u>NOT</u> FLATTENING OUT. IT IS STILL GOING DOWN AT ABOUT THE SAME ANGLE AND WE HAVE NOT YET HIT ANY INFANT MORTALITY RATE THAT IS, FOR OUR SOCIETY, THE IRREDUCIBLE MINIMUM.

OF EQUAL SIGNIFICANCE IS THE FACT THAT MOST OF THE INFANT LIVES WE ARE SAVING ARE <u>HEALTHY</u> LIVES. THERE IS NO REAL EVIDENCE SO FAR THAT THE INFANT MOR<u>BIDITY</u> RATE GOES UP AS THE INFANT MOR<u>TALITY</u> 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: OUR BEST INSTINCTIVE, VISCERAL RESPONSE TO THE DATA.

OF COURSE, WE DON'T NEED STATISTICAL CURVES THAT GO SHARPLY UP OR DOWN TO UNDERSTAND THE IMPACT A DISABLED INFANT HAS UPON ITS PARENTS AND UPON THE ATTENDING MEDICAL AND SOCIAL SERVICES STAFFS. 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 -- THE FAMILY AND THE HOSPITAL STAFF -- THEY ALL SHARE THE FEELINGS OF GUILT AND INADEQUACY.

BUT 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, THE RECREATIONAL EFFORTS, AND ALL THE OTHER ASPECTS OF THE BEST POSSIBLE QUALITY OF LIFE FOR THE DISABLED CHILD.

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 CARE FOR THEIR CHILD.

HOW DO WE DO THAT? WITHOUT INFRINGING ON ANY OF THE PRESENTATIONS SCHEDULED FOR THIS WORKSHOP, I WOULD LIKE TO SUGGEST THAT THE BEST ANSWER -- WHATEVER IT IS -- MUST DRAW UPON THESE PREREQUISITES:

THE MEDICAL AND SOCIAL SERVICES STAFFS THEMSELVES MUST BE FULLY KNOWLEDGEABLE ABOUT THE PARTICULAR DISEASE PROCESS OR DISABLING CONDITION AFFECTING THE NEWBORN...THEY MUST KNOW THE CONDITION OF THE INFANT ITSELF VERY WELL, THE HEALTH OF ITS ORGAN SYSTEMS, FOR EXAMPLE, AND ITS SENSORY AND SPEECH POTENTIAL...AND THE STAFFS MUST BE ABLE TO PUT THAT INFORMATION TOGETHER INTO A DISCREET, PERSONAL PORTRAIT OF THEIR INFANT PATIENT.

THESE PREREQUISITES CAN USUALLY BE MET. HOSPITALS ARE REALLY VERY HETEROGENEOUS INSTITUTIONS AND THEIR STAFFS EXHIBIT A FULL RANGE OF KNOWLEDGE AND EXPERIENCE. BUT THERE HAS TO BE A CERTAIN ADMINISTRATIVE TOUGHNESS OF JUDGMENT THAT WILL MAKE THE MOST CAPABLE HANDS IN THE INSTITUTION AVAILABLE TO DISABLED INFANTS AND THEIR FAMILIES. I THINK THAT IS THE KEY.

AS I INDICATED EARLIER, EVEN IF THEY DO GET THE BEST POSSIBLE GUIDANCE, DISABLED INFANTS AND THEIR FAMILIES MAY STILL FACE A FUTURE OF ENORMOUS HUMAN CHALLENGES IN THEIR COMMUNITIES AND IN THEIR OWN HOMES. HOW MUCH MORE DIFFICULT THEIR LIVES WILL BE, THEN, IF THE INITIAL HELP THEY RECEIVE FROM THE HOSPITAL STAFFS IS NOT THE VERY BEST THAT'S AVAILABLE. STAFF EXCELLENCE, THEREFORE, MUST FORM THE BASIS OF ALL OUR PROCEDURES, ROUTINES, AND WORK-PLANS.

WELL, WHAT MIGHT BE SOME OF THE QUALITIES OR ACTIONS THAT DISTINGUISH A CONCERNED AND CARING STAFF? WHAT MAKES THEM EXCELLENT? IS EXCELLENCE ACHIEVED THROUGH REVELATION OR THROUGH SENSITIVITY AND HARD WORK? I CAN TELL YOU THAT IT IS NOT THROUGH REVELATION. A GOOD STAFF IS OPEN TO THE NEEDS OF ITS PATIENTS AND DRAWS LIBERALLY FROM THE STRENGTHS OF ITS OWN MEMBERS. I KNOW THAT'S TRUE BECAUSE THAT IS HOW THE MEDICAL AND SOCIAL SERVICE STAFFS HERE AT CHILDREN'S HAVE EVOLVED OVER THE YEARS.

FOR A LONG TIME -- SOME 35 YEARS -- IT WAS MY PRIVILEGE TO SERVE WITH THE STAFF HERE AT C.H.O.P. DURING THAT TIME A CONSENSUS SEEMED TO HAVE EVOLVED, A CONSENSUS OF PRINCIPLES THAT UNDERLAY THE WAY WE CARED FOR OUR DISABLED NEWBORN PATIENTS AND THEIR FAMILIES. THESE PRINCPLES ARE NOT WRITTEN ANYWHERE...NO STAFF MEETING WAS EVER ASKED TO VOTE THEM UP OR DOWN...AND THEY WERE NEVER DELIVERED TO US ON THE BOARD OF TRUSTEES LETTERHEAD. YET, IN RETROSPECT I BELIEVE THESE FEW PRINCIPLES DID HAVE A STRONG THOUGH UNSPOKEN POWER AMONG US. AND I VENTURE TO SAY THEY ARE PRACTICED HERE STILL.

THE FIRST PRINCIPLE IS TO OBTAIN OPEN, DIRECT, AND PERSONAL COMMUNICATIONS WITH THE PARENTS OF A DISABLED NEWBORN.

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.

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. AT THAT POINT, THE PHYSICIAN-PATIENT RELATIONSHIP IS NO LONGER CASUAL. IT CANNOT BE FLIP. AND IT WON'T BE SHORT-TERM. THE PHYSICIAN HAS TO TRANSLATE THAT COMPLICATED MEDICAL TERMINOLOGY INTO WORDS THE PARENTS CAN UNDERSTAND -- AND NOT FEAR.

I THINK IT IS ESSENTIAL FOR THE ATTENDING PHYSICIAN IN PARTICULAR TO SIT DOWN WITH THE FAMILY AND CAREFULLY GO THROUGH THE NATURE OF THE INFANT'S CONDITION, WHAT THE MEDICAL EXPERIENCE WITH SUCH A CONDITION HAS BEEN SO FAR, WHAT KINDS OF OPTIONS ARE OPEN FOR IMMEDIATE ACTION, AND WHATS KIND OF OPTIONS MAY BE OPEN TO THE FAMILY AND THE PHYSICIAN LATER ON.

THE FIRST MEETING WITH PARENTS SHOULD FOCUS ENTIRELY ON DESCRIBING THE INFANT'S PARTICULAR PROBLEM. THE PARENTS NEED TO UNDERSTAND THIS AS COMPLETELY AS POSSIBLE, IN ORDER TO RATIONALLY TACKLE FAMILY, FINANCIAL, EMOTIONAL, AND OTHER ISSUES LATER ON. AT THIS TIME, PHYSICIANS AND OTHER STAFF NEED TO BE EXTREMELY CAUTIOUS ABOUT COMMENTING ON THE "QUALITY OF LIFE" THE TINY PATIENT WILL ULTIMATELY ENJOY. NO ONE, AFTER ALL, CAN PREDICT JUST HOW HAPPY OR SMART OR ACTIVE ANOTHER PERSON MAY BE AT SOME FUTURE TIME IN HIS OR HER LIFE. THE STAFF OUGHT NOT TO TRY.

THE PHYSICIAN SHOULD MEET WITH THE FAMILY IN PRIVATE AND IN A SETTING THAT IS NOT MEDICALLY OR SOCIALLY INTIMIDATING. THE TIMING MUST BE SUCH THAT <u>BOTH</u> PARENTS ARE AVAILABLE AND NOT PRESSED BY ANY OTHER APPOINTMENTS. UNLESS THE PARENTS INSIST, IT IS BEST NOT TO HAVE ANY "VERY GOOD FRIENDS" OR CLOSE RELATIVES PRESENT DURING THE FIRST MEETING OR TWO. THE PARENTS NEED TO RESPOND NATURALLY AND NOT BE WORRIED ABOUT ANOTHER'S JUDGMENT OF HOW WELL THEY HANDLE IT, NOR SHOULD THEY HAVE THE OPPORTUNITY TO SHIFT THE PROBLEM TO A THIRD PARTY. THE PHYSICIAN MUST ALSO BE AVAILABLE AND HAVE ENOUGH TIME TO WORK THROUGH ANY ESPECIALLY SENSITIVE INFORMATION. THEN THE PARENTS NEED SOME TIME TO THEMSELVES, AS THEY BEGIN TO FACE THE FUTURE. BUT THE PHYSICIAN AND OTHER STAFF SHOULD NEVER BE VERY FAR AWAY.

THERE ARE WAYS TO TRAIN MEDICAL STAFF -- PHYSICIANS OF ALL AGES, I MIGHT ADD -- TO HELP THEM PUT ASIDE THEIR BREEZY OR CASUAL 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.

I HAVE PUT THIS PRINCIPLE FIRST -- THE NEED TO ESTABLISH DIRECT, CLOSE, CANDID, AND PERSONAL COMMUNICATIONS -- BECAUSE IT IS SURELY THE ONE UPON WHICH ALL OTHERS MUST STAND.

A SECOND PRINCIPLE THAT IS PRACTICED BY AN EXCELLENT STAFF IS THIS: THE STAFF MUST RECOGNIZE AND UNDERSTAND THE NATURAL RESPONSES OF PARENTS TO THEIR DISABLED BABY...THEIR FEELINGS OF SADNESS, GUILT,

ANGER, EVEN OF SHAME. THE PARENTS WILL BE CONCERNED ABOUT THE JUDGMENTS OF THEIR NEIGHBORS AND THEIR FRIENDS. AND THEIR QUESTIONS BEGIN POURING OUT:

> "WHAT DOES IT MEAN?"..."WILL OUR BABY LIVE?"..."WHAT KIND OF LIFE WILL OUR CHILD HAVE?"..."IS IT THE RESULT OF SOMETHING WE DID?"... "IS IT BECAUSE WE SHOULD HAVE DONE SOMETHING AND DIDN'T?"

THE QUESTIONS MAY COME IN A RUSH, BUT THE ANSWERS SHOULD BE GIVEN ONLY AFTER A GREAT DEAL OF CAREFUL THOUGHT. THE STAFF NOW REPRESENTS NOT ONLY MEDICAL CARE -- BUT THE OUTSIDE WORLD AS WELL. IT MAY NOT BE FAIR FOR THE STAFF TO HAVE TO CARRY THIS ROLE RESPONSIBILITY ALSO. BUT IN SUCH INTENSE HUMAN SITUATIONS, A STAFF HAS MANY ASSIGNMENTS AND FEW CHOICES.

NO MATTER HOW SERIOUS THE INFANT'S CONDITION IS AND NO MATTER HOW THE MEDICAL TEAM RESPONDS, IT IS ESSENTIAL THAT STAFF MEMBERS 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. WE NEED TO TRANSMIT THIS UNDERSTANDING TO PARENTS, EVEN AS THEY VERBALIZE THEIR MOST TROUBLING THOUGHTS.

BUT I HAVE A PARTICULAR CAVEAT TO RAISE HERE. I WANT TO 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. AND WE NEED TO BUILD ON THEIR STRENGTHS.

I DON'T WANT TO GIVE A FALSE PICTURE HERE. WE CAN HELP PARENTS BECOME A CLOSE AND LOVING FAMILY RIGHT AT THE POINT WHERE THEY ARE CONFRONTING A DIFFICULT FUTURE. BUT THAT HELP WILL ONLY WORK IF THE PARENTS ARE CAPABLE AND DO WANT IT TO WORK. 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 TO THE STATE, 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 NUMBER OF MOTHERS WHO TAKE HOME INFANTS BORN WITH SINGLE OR MULTIPLE DISABILITIES...WHO TRY TO ABSORB THE INFORMATION ABOUT THE CARE THEY NEED...OR WHO TRY TO COPE 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 DECISIONS TO GIVE UP A CHILD WERE MADE BY PARENTS WHO WOULD HAVE BEEN REWARDED A HUNDRED-FOLD IF THEY HAD NOT GIVEN IT UP BUT INSTEAD HAD 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.

THE THIRD PRINCIPLE EMPHASIZES THE <u>FULL PARTICIPATION OF THE PARENTS AND SIBLINGS IN ALL THE PROCESSES OF MEDICAL CARE</u>. IN AS MANY WAYS AS POSSIBLE, A STAFF NEEDS TO DEMONSTRATE TO THE PARENTS THAT THEY ARE NEEDED AS PARTNERS. IT IS NOT ARTIFICIAL, NOT SOME RUSE TO TRICK THEM INTO DOING SOMETHING THEY OUGHT NOT TO DO. QUITE THE REVERSE. THERE IS NO SUBSTITUTE FOR A LOVING, CARING FAMILY.

AS SOON AS POSSIBLE, THE PHYSICIAN AND OTHER STAFF MEMBERS SHOULD TRY TO GET THE CHILD LITERALLY INTO THE HANDS OF THE FAMILY. A PARENT

STARING THROUGH A PANE OF GLASS AT A LITTLE BABY IN A COVERED ISOLETTE OVER IN THE CORNER IS JUST NOT MY IDEA OF "FAMILY TOGETHERNESS." I WAS IN THE HABIT OF URGING PARENTS TO VISIT THEIR CHILD AS SOON AND AS OFTEN AS POSSIBLE. OTHER FAMILY MEMBERS -- GRANDPARENTS, SIBLINGS, AUNTS, OR UNCLES -- WERE ALSO ENCOURAGED TO STOP BY. <u>I</u> WAS PROUD OF THE BABY AND I WANTED <u>THEM</u> TO BE, TOO. EVEN THOUGH THE BABY MAY BE BANDAGED, INTUBATED, MONITORED, AND FED WITH A HYPERALIMENTATION LINE, THE PARENTS CAN AND SHOULD TOUCH THE CHILD...IF POSSIBLE, THEY SHOULD ALSO HOLD IT AND CUDDLE IT.

AS A LAST PRINCIPLE -- FOR MY PURPOSES THIS MORNING, AT ANY RATE -- I WOULD SAY THAT THE MEDICAL AND SOCIAL SERVICE STAFFS NEED TO <u>PLAY A POSITIVE, ACTIVE ROLE IN LINKING UP THE CHILD AND ITS FAMILY WITH THE AVAILABLE SOCIAL AND MEDICAL SUPPORT GROUPS IN THE COMMUNITY</u>.

IN OTHER CONTEXTS AND FOR MORE ROUTINE SITUATIONS WE ALL ADVOCATE <u>CONTINUITY OF CARE</u> AND <u>TOTAL CARE</u> FOR OUR PATIENTS AND CLIENTS. HOW MUCH MORE IMPORTANT IS THIS KIND OF APPROACH FOR INFANTS WITH DISABILITIES. THE MEDICAL AND SOCIAL SERVICE STAFFS WHO TAKE THIS PRINCIPLE SERIOUSLY HAVE THE SET OF MIND AND THE FIRM PROFESSIONAL COMMITMENT TO BECOME ADVOCATES FOR THEIR PATIENTS AND THE PARENTS. IN THAT ROLE, THEY HELP MAKE THE VITAL CONNECTIONS BETWEEN HOME AND COMMUNITY RESOURCES.

PEOPLE WHO WORK IN HOSPITALS, CLINICS, SCHOOLS OR OTHER SERVICE INSTITUTIONS ARE USUALLY FAMILIAR WITH MOST OF THE COMMUNITY SERVICES NETWORK -- AND VERY OFTEN THEY ASSUME THAT EVERYONE ELSE HAS THE SAME INFORMATION. BUT, IN POINT OF FACT, MOST PEOPLE DO NOT.

MOST PEOPLE MAY, ON OCCASION, HAVE USED ONE OR ANOTHER SOCIAL SERVICE OR HEALTH AGENCY OR MAY EVEN HAVE REGULARLY CONTRIBUTED TO CERTAIN VOLUNTARY ORGANIZATIONS CONCERNED WITH A PARTICULAR DISEASE OR DISABILITY. BUT WHEN FACED WITH 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.

IF THE PARENTS AND THE STAFF HAVE FORMED A RELATIONSHIP BASED UPON THE PRINCIPLES I'VE TALKED ABOUT THIS MORNING -- EVEN IF THEY HAVE ALREADY MADE A FIRM COMMITMENT TO CARE FOR THEIR CHILD AND GIVE IT ALL THE LOVE IT NEEDS -- THEY MAY STILL BE TOTALLY OVERWHELMED BY THE BYZANTINE COMPLEXITY OF OUR SOCIAL SERVICE DELIVERY SYSTEM. SOCIETY MAY YET SEEM TO BE CONSPIRING AGAINST THEM.

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. FRANKLY, SURGEONS ARE REALLY NOT VERY GOOD AT IT. UNFORTUNATELY, THEY ARE NOT ALONE. MOST PHYSICIANS ARE JUST NOT THAT FAMILIAR WITH THE KIND OF HELP THAT'S AVAILABLE. AT BEST THEY MAY ONLY HAVE A SENSE THAT THERE _IS_ SOME HELP OUT THERE. BUT I HONESTLY DON'T BELIEVE IT TAKES THAT MUCH EFFORT TO FIND THE APPROPRIATE SOCIAL SERVICE AGENCY FOR A DISABLED INFANT AND ITS FAMILY.

I THINK IT'S IMPORTANT TO REMEMBER THAT "SOCIAL SERVICES" AS SUCH ARE NOT EXCLUSIVELY THE PROVINCE OF THE "SOCIAL SERVICE WORKER." CERTAINLY WE EXPECT A GREATER PROFESSIONALISM FROM A PERSON TRAINED IN THIS FIELD, BUT THERE ARE MANY OTHER DISCIPLINES WITHIN THE HOSPITAL COMMUNITY THAT CAN BE HELPFUL, TOO. I AM THINKING IN PARTICULAR OF THAT NEW AND EXTRAORDINARY BREED OF INDIVIDUAL KNOWN AS THE "NEONATAL INTENSIVE CARE NURSE." THEY BRING TO THEIR JOB A TOTAL COMMITMENT TO CHILD HEALTH AND WELFARE...NOT IN THE ABSTRACT, BUT IN THE REAL WORLD OF DAY-TO-DAY CARE FOR TINY VULNERABLE, RUPTURED LIVES. I DON'T THINK

IT'S AN OVER-STATEMENT TO SAY THAT MANY OF THESE NURSES DISPLAY VERY STRONG PARENTAL FEELINGS TOWARD THEIR DISABLED PATIENTS AND I HAVE OFTEN INVITED ONE OF THEM TO JOIN ME IN ONE OR ANOTHER OF MY PARENT CONFERENCES.

I SHOULD ADD THAT, WHEN I DID TAKE PART IN THAT EFFORT TO SECURE COMMUNITY SOCIAL AND HEALTH SERVICES FOR MY PATIENTS, THE OCCASION WAS USUALLY OF MY OWN CHOOSING, BASED UPON A CLOSENESS THAT MAY HAVE DEVELOPED AMONG ME, MY PATIENT, AND ITS PARENTS. ALSO, I WAS IN THE MIDDLE OF THESE SITUATIONS FOR MANY, MANY YEARS AND SAW A NUMBER OF TODAY'S SERVICES BEING DEVELOPED FROM SCRATCH. ALSO, I MUST CONFESS TO A LITTLE PREJUDICE. I THOUGHT THEN -- AND I CONTINUE TO THINK -- THAT THE "SOCIAL SERVICES" AVAILABLE FROM AMONG ALL WHO TRIED TO PROVIDE IT AT THE CHILDREN'S HOSPITAL OF PHILADELPHIA WAS -- AND STILL IS -- JUST FIRST-RATE.

BUT WE NEED TO KEEP OUR EYES WIDE OPEN, WHEN WE INTRODUCE THE PATIENT'S FAMILY TO THE WORLD OF SOCIAL SERVICES. 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 INFANTS. 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. AND, LIKE ALL MIRACLES, YOU CANNOT PREDICT HOW THIS ONE WILL TURN OUT EITHER.

THAT WORD -- "MIRACLE" -- IS BEING WORKED VERY HARD THESE DAYS. IT SEEMS TO BE IN THE LEXICON OF EVERY REPORTER IN THE HOSPITAL AUDITORIUM IN SALT LAKE CITY, UTAH. IT TENDS TO BE USED WITH EVERY NEW DEVELOPMENT IN MEDICAL TECHNOLOGY, REGARDLESS OF THE OUTCOMES. CERTAINLY THERE MAY BE MUCH THAT SEEMS TO BE "MIRACULOUS" ABOUT INFANT INTENSIVE CARE TECHNOLOGY, FOR EXAMPLE, BUT THE OUTCOMES ARE ALSO MIXED.

I MENTIONED A FEW MOMENTS AGO THAT THE INFANT MORTALITY RATE IS COMING DOWN AND THAT, AS NEAR AS WE COULD TELL, MOST OF THE BABIES WE ARE SAVING ARE HEALTHY BABIES. BUT THE PICTURE IS REALLY NOT THAT SIMPLE.

A NUMBER OF THE INFANTS WE ARE SAVING ARE PREMATURE OR ARRIVE WITH A LOW BIRTH WEIGHT OR ARE IMMATURE IN SOME ASPECT OF THEIR DEVELOPMENT AND EXHIBIT RESPIRATORY DISTRESS. THEY MAY BE IMMEDIATELY TAKEN TO AN

INFANT INTENSIVE CARE UNIT, OR TRANSPORTED TO ONE, AND PUT ON A RESPIRATOR. THESE BABIES ARE USUALLY THE ONES THAT MIGHT NOT HAVE SURVIVED THEIR BIRTH JUST A FEW YEARS AGO. TODAY THEY ARE ALIVE. BUT THEY REPRESENT A NEW CATEGORY OF DISABLED CHILD -- A CATEGORY CREATED BY THE I.I.C.U. TECHNOLOGY. THE ALTERNATIVE FOR SUCH BABIES HAD ONCE BEEN DEATH.

AT PHILADELPHIA CHILDREN'S, WHEN WE WERE DEVELOPING THIS LIFE-SAVING TECHNOLOGY, THE COST OF IN-PATIENT THERAPY WAS ABOUT $1,000 PER DAY PER RESPIRATOR-DEPENDENT CHILD. ONE SURVEY SHOWED THAT, IN THE 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...AND, DEPENDING UPON THE CIRCUMSTANCES, POSSIBLY DELAYED FOREVER.

I KNOW OTHERS ON THE PROGRAM TODAY AND TOMORROW ARE GOING TO SPEAK MORE PARTICULARLY TO THIS EXAMPLE. BUT I WANT TO UNDERSCORE ITS SIGNIFICANCE:

FIRST, THE RESPIRATOR-DEPENDENT CHILD IS A CREATURE OF OUR NEW TECHNOLOGY AND, IN FACT, NEEDS ADDITIONAL TECHNOLOGY TO RELIEVE THE FIX OF DEPENDENCY THAT IT IS IN. THIS IS NO LONGER A UNIQUE PROBLEM FOR MEDICINE. IT IS VERY USEFUL, THEREFORE, TO TAKE A CLOSE LOOK AT THE PROBLEM OF THE RESPIRATOR-DEPENDENT CHILD IN ORDER TO SEARCH OUT THOSE CONCEPTS AND APPROACHES THAT MAY PRODUCE WORKABLE SOLUTIONS IN OTHER, SIMILAR SITUATIONS. THE WAY WE HANDLE THIS PARTICULAR PROBLEM MAY IN FACT BE A KIND OF MODEL FOR THE WAY WE MIGHT DEAL WITH MANY OTHER CONGENITAL ANOMALIES THAT TAX OUR HUMAN AND MATERIAL RESOURCES.

SECOND, THE PROBLEM OF THE RESPIRATOR-DEPENDENT CHILD CONCERNS TECHNOLOGY...BUT NOT EXCLUSIVELY. FUNDAMENTAL TO THE HANDLING OF THIS PROBLEM, I BELIEVE, ARE THE SEVERAL PRINCIPLES PROMOTING STAFF-FAMILY INTERPLAY. THIS IS WHERE TECHNOLOGY LEAVES OFF AND BASIC HUMANITY TAKES OVER.

THIRD, IT PROVIDES US WITH A RATHER CLEAR ASSESSMENT OF HOW ADEQUATE -- OR INADEQUATE -- OUR SOCIAL SERVICES MAY BE NOT JUST FOR PATIENT CARE BUT FOR TOTAL FAMILY CARE AS WELL.

AND FOURTH, IT IS POSSIBLE FOR US TO BEGIN SOME LONGITUDINAL STUDIES OF HOW THESE PATIENTS DO BOTH IN THE HOSPITAL SETTING AND IN THE HOME, WHAT THE COSTS ARE AT EACH PLACE, WHAT THE EFFECTS ARE OF CHANGES IN TECHNOLOGY, WHAT THE COST/PRICE HISTORY IS, AND SO ON.

SUCH AN OPPORTUNITY RARELY APPEARS IN WHICH THESE FOUR ELEMENTS ARE PRESENT. BUT THIS WORKSHOP DOES OFFER US A KIND OF SURROGATE OPPORTUNITY. SO I AM DELIGHTED TO SEE ALL OF YOU HERE, LOOKING HARD AT THE OVERALL PROBLEM OF PROVIDING BETTER CARE FOR DISABLED CHILDREN AND THEIR FAMILIES, AND ALSO FOCUSING IN ON THE SPECIFIC EXAMPLE -- OR "MODEL" -- OF THE CARE FOR THE RESPIRATOR-DEPENDENT CHILD AND ITS FAMILY.

AGAIN, LET ME THANK EACH ONE OF YOU FOR COMING TODAY, FOR CONTRIBUTING YOUR TIME, KNOWLEDGE, AND EXPERIENCE -- AND YOUR BASIC HUMANITY -- TO THIS PROBLEM. IN THE LONG RUN, I THINK THAT THE WAY WE DEAL WITH PROBLEMS LIKE THIS REVEALS JUST WHAT KIND OF A SOCIETY WE ARE.

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