

ORIGINAL

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PRIVATE THOUGHTS ON PUBLIC ISSUES

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GLASGOW, SCOTLAND

SEPTEMBER 30, 1987

(GREETINGS TO HOSTS, GUESTS, FRIENDS, ETC.)

IT IS AN HONOR AND A GREAT PERSONAL PLEASURE FOR ME TO BE  
HERE THIS EVENING.

I WANT TO TALK ABOUT MEDICINE AND PUBLIC SERVICE AND  
PERSONAL CODES OF CONDUCT AND HOW ALL THREE MAY COINCIDE.

AND I'D LIKE TO DO THIS BY RECOUNTING SEVERAL BRIEF STORIES  
THAT CENTER AROUND CHILDREN. SOME OF THEM HAD NAMES...AND SOME  
DID NOT.

BUT EACH ONE OF THEM TOUCHED A CHORD IN MY OWN SOUL AS A  
DOCTOR AND EACH ONE HELPED TO SHAPE THE KIND OF SURGEON GENERAL I  
HAVE BECOME.

I MUST CONFESS THAT, BACK IN 1981, WHEN PRESIDENT REAGAN ASKED ME TO JOIN THE GOVERNMENT TO BE THE SURGEON GENERAL OF THE U.S. PUBLIC HEALTH SERVICE, I DID NOT GO THROUGH AS MUCH SOUL-SEARCHING AS PERHAPS I SHOULD HAVE.

I HAD READ BOOKS AND ARTICLES ABOUT -- AND BY -- PRIVATE CITIZENS WHO HAD TAKEN THEIR TURN AT PUBLIC SERVICE. BUT, I NOW REALIZE, I HADN'T REALLY ABSORBED THEIR LESSONS ALL THAT WELL. MY DECISION IN 1981 WAS NOT THE RESULT OF A CAREFULLY BALANCED ARGUMENT OF PRO AND CON.

BUT IN MY OWN DEFENSE, I MUST SAY THAT IT IS RARE THAT ANYONE CAN BE ALTOGETHER RATIONAL, IF THEY ARE ASKED BY THE PRESIDENT OF THE UNITED STATES TO DO A JOB.

BUT LET ME BE QUITE CLEAR ABOUT THIS. I LOVE EVERY MINUTE OF MY JOB. THE FRUSTRATIONS ARE FAR OUTWEIGHED BY THE SATISFACTIONS OF ACHIEVEMENT. I CAN TELL YOU UNEQUIVOCALLY THAT I HAVE NO REGRETS ABOUT ACCEPTING PRESIDENT REAGAN'S INVITATION.

IN ADDITION, MY PARTICULAR EXPERIENCE WAS SOMEWHAT SPECIAL. WHEN THE PRESIDENT NOMINATED ME FOR THE POST OF SURGEON GENERAL, I WAS NOT ONLY GOING TO BE THE OLDEST PERSON EVER TO HAVE THAT JOB -- A MATTER OF SOME CONTENTION AT THE TIME -- BUT I HAD A REPUTATION FOR HOLDING CERTAIN CONTROVERSIAL VIEWS. LET ME CORRECT THAT: I HELD CERTAIN VIEWS WHICH OTHER PEOPLE FOUND TO BE CONTROVERSIAL.

FOR ONE THING, I WAS -- AND STILL AM -- AN ADVOCATE FOR PEOPLE WHO ARE PHYSICALLY OR MENTALLY DISABLED. THEY ARE SOMETIMES CALLED "THE HANDICAPPED," BUT THAT'S A MISTAKE. IT IS SOCIETY THAT PLACES A HANDICAP ON PEOPLE WHO ARE DISABLED. SOCIETY CAN ALSO LIBERATE THEM OR HELP THEM OVERCOME THEIR DISABILITIES. BUT DISABLED PEOPLE ARE NOT -- IPSO FACTO -- HANDICAPPED PEOPLE.

NATURALLY, AS SOMEONE HOLDING THAT POINT OF VIEW, I AM AUTOMATICALLY ON ONE SIDE OF AN ARGUMENT -- ANY ARGUMENT -- CONCERNING DISABLED PERSONS AND THEIR NEEDS AND THEIR RIGHTS. AND I'VE NEVER HAD A PROBLEM CHOOSING MY SIDE.

SOME CRITICS OF MY NOMINATION WERE ALSO CONVINCED THAT I WOULD COME TO THE JOB OF SURGEON GENERAL WITH MANY PREJUDICES AND PRE-CONCEIVED IDEAS ABOUT DISABLED PEOPLE. THEY THOUGHT I WOULD HAVE A HARD TIME BEING "FAIR." IN OTHER WORDS, AS THE ADVOCATE FOR THE DISABLED, I PROBABLY COULD NOT BE COUNTED ON TO EITHER IGNORE THEM OR IN SOME OTHER WAY ACT AGAINST THEIR BEST INTERESTS.

AND I MUST SAY THAT MY CRITICS WERE ABSOLUTELY RIGHT. I HAVE MADE NO BONES ABOUT WANTING TO BE AN ADVOCATE FOR THE DISABLED COMMUNITY IN MY COUNTRY. AND I WAS -- AND I REMAIN -- THOROUGHLY SURPRISED AND DISTRESSED THAT SUCH A POSITION COULD BE CONSIDERED EVEN FAINTLY SUSPICIOUS.

WELL, WHAT HAPPENS WHEN A PERSON WITH STRONG, CONTROVERSIAL, AND PUBLICLY ADVERTISED IDEAS ENTERS GOVERNMENT? MUST YOU DEPOSIT YOUR RELIGIOUS BELIEFS IN A BLIND TRUST? SHOULD YOU DONATE YOUR MORAL VALUES TO CHARITY? BEFORE YOU MOVE TO WASHINGTON, SHOULD YOU HIDE YOUR ETHICS IN AN ATTIC TRUNK?

I SAY, "NO...NONE OF THE ABOVE."

I TRULY BELIEVE THAT THE BEST APPROACH YOU CAN MAKE TO PUBLIC SERVICE IS TO GIVE IT EVERYTHING YOU HAVE OF JUST WHAT IT IS THAT YOU DO HAVE...TO DRAW TO THE FULLEST EXTENT FROM YOUR STOREHOUSE OF KNOWLEDGE AND PERSONAL LIFE EXPERIENCE...TO SQUEEZE OUT EVERY OUNCE OF GOOD JUDGMENT, OF DEEP FELLOW FEELING, AND OF LOVE OF COUNTRY.

IN OTHER WORDS, ENTERING PUBLIC SERVICE REQUIRES YOU TO BE THE VERY BEST PERSON YOU KNOW HOW TO BE, WHICH IS THE SAME AS BEING THE VERY BEST CITIZEN YOU KNOW HOW TO BE.

SINCE NOVEMBER 1981, WHEN I WAS SWORN INTO MY POSITION, I'VE HAD A NUMBER OF OPPORTUNITIES TO TEST MY ABILITY TO APPLY TO THE PUBLIC BUSINESS THE STUFF OF WHO AND WHAT I AM. I WILL ADMIT THAT I WAS NOT ALWAYS QUICK ENOUGH OR SURE ENOUGH TO SEIZE SOME OF THOSE OPPORTUNITIES AS THEY WENT BY. BUT WITH OTHERS I WAS MORE SWIFT AND MORE FORTUNATE.

I HAVE LEARNED THAT, WHEN AN IDEA'S TIME HAS COME -- AND IT IS ON YOUR WATCH -- YOU MUST SEIZE THE MOMENT...YOU MUST MOVE TO DEVELOP IT.

LET ME BEGIN BY RECALLING THE SUMMER OF 1981, WHEN THE BECKETT FAMILY OF CEDAR RAPIDS, IOWA, IN THE HEARTLAND OF THE UNITED STATES, COMPLAINED OF THE ILLOGIC OF A GOVERNMENT PROGRAM THAT SUPPORTS THE DELIVERY OF MEDICAL CARE,

THEIR 3-YEAR-OLD DAUGHTER, KATIE BECKETT, WAS IN THE HOSPITAL, WHERE SHE HAD BEEN FOR THE PAST YEAR AND A HALF, RECOVERING FROM A SERIOUS CASE OF VIRAL ENCEPHALITIS.

IN THE HOSPITAL SHE WAS MAINTAINED ON RESPIRATOR THERAPY AROUND THE CLOCK. SUCH CARE WAS COSTING \$12,000 A MONTH. AND YOU COULD ADD TO THAT THE COSTS OF THE BECKETT FAMILY GOING TO AND FROM THE HOSPITAL TO SEE THEIR DAUGHTER AND TO KEEP THE BOND OF LOVE STRONG BETWEEN THEM.



THEY WANTED TO TAKE HER HOME. BUT IF THEY DID, THEY WOULD HAVE FORFEITED THE GOVERNMENT'S MEDICAID PAYMENT OF \$12,000 A MONTH FOR KATIE'S IN-PATIENT TREATMENT FOR THE SIMPLE REASON THAT HOME CARE IS NOT COVERED.

BUT THEY WERE ON THE RIGHT TRACK, BECAUSE IF KATIE WENT HOME, THE COST OF CARE WOULD THEN DROP TO ONLY \$2,000 A MONTH. THE GOVERNMENT WOULD SAVE \$10,000 A MONTH AND, MOST IMPORTANT OF ALL, KATIE BECKETT WOULD BE BACK ONCE AGAIN IN THE FULL-TIME CARE OF HER OWN FAMILY.

THE BECKETTS APPEALED TO THEIR GOVERNMENT. THEIR APPEAL WOUND ITS WAY UP TO THE PRESIDENT, WHO, IN TURN, GAVE US ORDERS TO STRAIGHTEN OUT THE "KATIE BECKETT MATTER."

THE ASSIGNMENT CAME TO OUR DEPARTMENT AND I, BECAUSE OF MY 35 YEARS IN PEDIATRIC SURGERY, WAS THE PERSON WHO PROBABLY BEST UNDERSTOOD THE MEDICAL ISSUE SIDE AS WELL AS THE HUMAN SIDE OF THE CASE. I WAS ASKED TO TAKE ON THE TASK...ONE OF THE FIRST OF MY NEW CAREER AS SURGEON GENERAL.

UP TO THAT TIME, I HAD SPENT MY PROFESSIONAL LIFE REPAIRING THE PHYSICAL DISABILITIES OF BABIES AND SMALL CHILDREN. DURING THAT TIME MY COLLEAGUES AND I HAD BEEN SUCCESSFUL IN GETTING 17 CHILDREN -- 17 "KATIE BECKETTS" -- OUT OF THE HOSPITAL AND BACK TO THEIR OWN HOMES, EVEN THOUGH VENTILATOR DEPENDENT.

FOR EACH OF THOSE CHILDREN, WE HAD ALSO REDUCED THE CHANCES OF NOSOCOMIAL, OR HOSPITAL-INDUCED, INFECTION...INCREASED THE QUOTIENT OF LOVE AND ATTENTION AVAILABLE TO THEM EVERY DAY...AND BROUGHT DOWN THE COSTS OF THEIR CARE FROM ABOUT \$1,000 A DAY TO \$400 A WEEK.

SO I KNEW THE PRESIDENT WAS ON THE RIGHT TRACK AND I SET TO WORK.

THE RESULTS HAVE BEEN VERY GRATIFYING.

FIRST, WE WERE ABLE TO SEND KATIE BECKETT HOME...WITH HER FAMILY AND WITH FINANCIAL ASSISTANCE FROM THE GOVERNMENT, AT A FRACTION OF THE COST IN THE HOSPITAL.

NEXT, WE SET UP A BOARD OF REVIEW AND BEGAN TO DO THE SAME THING FOR MANY OTHER FAMILIES LIKE THE BECKETTS. IN FACT, THE BOARD BECAME KNOWN AS "THE KATIE BECKETT REVIEW BOARD."

THE BOARD HAS SINCE GONE OUT OF BUSINESS BECAUSE BOTH THE PRESIDENT AND THE CONGRESS CHANGED THE LAW AND THE EXCEPTIONS HAVE NOW BECOME THE RULE. THE KATIE BECKETTS OF THE UNITED STATES HAVE WON.

WE LEARNED MANY THINGS BY THIS EXPERIENCE, BUT -- IN RETROSPECT -- ONE CLEAR LESSON WE LEARNED WAS THAT THE GOVERNMENT WAS COMMITTED TO HELP IN CASES LIKE THIS AND IT WOULD SOMEHOW COME UP WITH THE MONEY TO PAY FOR THAT HELP.

THE ONLY QUESTION FOR US WAS WHETHER OR NOT THE GOVERNMENT WAS SPENDING ITS MONEY IN THE MOST EFFICIENT WAY. I BELIEVE WE CAME UP WITH A MUCH BETTER WAY.

INCIDENTALLY, KATIE IS OFF THE VENTILATOR, WELL, AND LIVING WITH HER FAMILY.

THE NEXT ISSUE TO INVOLVE ME WAS THAT OF ORGAN TRANSPLANTATION. MANY PEOPLE NEED NEW ORGANS...BUT THERE ARE NOT AS MANY DONORS...AND THE TWO ARE HARDLY EVER IN THE SAME PLACE AT THE SAME TIME.

AGAIN, THIS CAME TO THE ATTENTION OF PRESIDENT REAGAN, WHO MADE A PUBLIC APPEARANCE OVER THE RADIO TO FIND AN ORGAN FOR AN 11-MONTH-OLD BOY NAMED JAMIE FISKE. HE HAD A WHITE HOUSE PLANE STANDING BY TO FLY JAMIE AND/OR A DONOR ORGAN ANYWHERE IN THE UNITED STATES.

GRANTED, THAT WAS A VERY INEFFICIENT WAY FOR THE GOVERNMENT TO PROCEED...BUT IT DID GET EVERYONE'S ATTENTION.

JAMIE FISKE'S PROBLEM WAS MUCH MORE COMPLICATED THAN KATIE BECKETT'S. KATIE NEEDED A PIECE OF EQUIPMENT. AND EQUIPMENT CAN BE MANUFACTURED AS NEEDED OR MANUFACTURED AND STORED UNTIL IT'S NEEDED.

BUT THAT'S NOT THE CASE AT ALL WITH MOST HUMAN ORGANS.

JAMIE GOT HIS LIVER AND IS ALIVE AND WELL TODAY.

I WAS FAMILIAR WITH THIS ISSUE, SINCE I HAD PERFORMED COUNTLESS PROCEDURES ON CHILDREN WITH BILIARY ATRESIA, WHICH IS USUALLY THE PEDIATRIC CAUSE FOR LIVER FAILURE AND THE NEED FOR A TRANSPLANT.

I CONVENED A "SURGEON GENERAL'S WORKSHOP"...THIS TIME THE PARTICIPANTS WERE EXPERTS IN ORGAN TRANSPLANTATION. WE MET IN A SMALL TOWN OUTSIDE WASHINGTON.

WE PRODUCED GOOD RESULTS.

FIRST, WE AGREED THAT THE PRIVATE SECTOR OUGHT TO ASSUME THE LEADERSHIP IN THIS ISSUE. AND WE CAME AWAY WITH A PLAN OF WHAT TO DO NEXT. SUBSEQUENTLY, WE FORMED AN "AMERICAN COUNCIL ON TRANSPLANTATION," A KIND OF UMBRELLA ORGANIZATION FOR ALL GROUPS -- BOTH PUBLIC AND PRIVATE -- WHO ARE INVOLVED IN THIS ISSUE.

THE AMERICAN COUNCIL HAS ADDRESSED SUCH QUESTIONS AS THE AVAILABILITY OF ORGANS, THE MORAL AND ETHICAL ISSUES SURROUNDING THE QUEUE OF WAITING PATIENTS, THE RESEARCH TO BE ACCOMPLISHED, THE LEGAL ISSUES TO BE RESOLVED, THE ROLE OF THE MEDIA, AND SO ON.

UNLIKE THE "KATIE BECKETT" STORY, THIS ONE HAS NO CLEAR, HAPPY ENDING.

ANOTHER CHILD, ASHLEY BAILEY, NEEDED A LIVER. THE FAMILY JUST DID NOT SEEM TO WANT TO STAND IN THE QUEUE WAITING. SHE TOO CAME TO THE ATTENTION OF THE PRESIDENT AND WHEN SHE WAS IN EXTREMIS THE PRESIDENT WENT ON RADIO AND APPEALED FOR A LIVER.

THE NEXT HE KNEW WAS THE HEADLINES "ASHLEY BAILEY DIES IN SPITE OF REAGAN APPEAL". HE WAS VERY DISAPPOINTED. IT REMAINED FOR ME TO GET A NOTE ON HIS DESK AFTER WHICH HE CALLED ME. I COULD TELL HIM HIS APPEAL BROUGHT 40 RESPONSES, BUT NO SURGEON WOULD PUT ASHLEY AT THE TOP OF THE LIST KNOWING ANOTHER PERSON PATIENTLY WAITING WOULD DIE AS A RESULT.



AND MANY OTHER CHILDREN AND ADULTS AS WELL DIE BEFORE AN APPROPRIATE ORGAN IS FOUND.

FOR SOME PROBLEMS MONEY IS NOT THE REAL ISSUE. AND THAT IS THE CASE HERE. WHILE ORGAN TRANSPLANTATION IS VERY EXPENSIVE, IT IS ALSO -- MORE IMPORTANTLY -- BEYOND THE CONTROL OF MEDICINE OR LAW OR ECONOMICS.

THERE APPEARS TO BE AN IRREDUCIBLE LEVEL OF TRAGEDY IN SOME AREAS OF MEDICINE AND HEALTH, SOMETHING WE DO NOT LIKE TO RECOGNIZE IN THESE DAYS OF MIRACULOUS MEDICAL TECHNOLOGY. BUT IT IS TRUE. AND IN 1984 WE HAD TO FACE THE FACT THAT NOT EVEN THE PERSONAL INTERVENTION OF THE PRESIDENT OF THE UNITED STATES COULD PRODUCE A LIVER FOR THE BODY OF A DYING CHILD. AND I THINK THE ETHICS WERE ON TARGET.

THIS YEAR WE EXPECT TO TRANSPLANT ABOUT 1,000 LIVERS WHILE THE NUMBER OF HEARTS TRANSPLANTED WILL PROBABLY EXCEED 1,300. AND PREDICTIONS INDICATE THAT WE WILL SURPASS LAST YEAR'S NUMBERS. AND 9,000 KIDNEYS WILL FIND NEW OWNERS.

MY NEXT EXAMPLE INVOLVES AN UNKNOWN INFANT WHO, FOR ITS BRIEF LIFE, HAD BEEN KNOWN ONLY AS "BABY DOE."

"BABY DOE" WAS BORN IN APRIL 1982 WITH ESOPHAGEAL ATRESIA. THE BABY ALSO HAD DOWN SYNDROME.

A SURGEON AT THE HOSPITAL INFORMED THE PARENTS THAT THE INFANT HAD A 50-50 CHANCE OF SURVIVING CORRECTIVE SURGERY. I AND MANY OF MY COLLEAGUES HAD DONE SUCH SURGERY OVER THE YEARS AND WE KNEW THAT THE ODDS WERE FAR BETTER THAN THAT. IN THE LAST 8 YEARS OF MY EXPERIENCE, I LOST NO FULL TERM BABY, AND IN PREMATURES MY SURVIVAL WAS 88%. OUR TOTAL EXPERIENCE WHEN I LEFT PHILADELPHIA IN 1982 WAS 475 INFANTS WITH SOME VARIATION ON THE USUAL ANOMALY.

EVEN TODAY, AFTER MOST OF THE DUST HAS SETTLED, THERE IS NO COMPLETE AGREEMENT AS TO WHAT REALLY HAPPENED TO BABY DOE, WHAT IT ALL MEANS, AND WHAT WE SHOULD HAVE DONE NEXT. AND IN THIS RESPECT, I THINK THE GOVERNMENT ACCURATELY REFLECTS THE FEELING THAT IS ABROAD IN THE LAND GENERALLY.

"BABY DOE" WAS BORN IN A COMMUNITY HOSPITAL IN INDIANA, ON APRIL 8, 1982, WITH MULTIPLE CONGENITAL DEFECTS, INCLUDING AN ESOPHAGEAL OBSTRUCTION AND DOWN SYNDROME. THE PARENTS AND THE OBSTETRICIAN DECIDED HE SHOULD DIE.

BUT MEDICAL OPINION AT THE HOSPITAL WAS DIVIDED. IT'S IMPORTANT TO REMEMBER THAT FACT, BECAUSE IT HAS BEEN ARGUED THAT THE POSITION TAKEN BY THE GOVERNMENT AND BY SOME CIVIL RIGHTS ADVOCATES IN THIS CASE HAS BEEN A POSITION AGAINST THE JUDGMENT OF PHYSICIANS. BUT, FROM THE VERY BEGINNING, THERE WAS NO SINGLE MEDICAL POSITION...THE "BABY DOE" CASE HAD 2 SIDES TO ALMOST EVERY QUESTION RAISED...

2 SIDES AS TO WHAT THE TREATMENT OUGHT TO BE...

2 SIDES AS TO WHO MAKES SUCH DECISIONS...

2 SIDES AS TO HOW SUCH DECISIONS ARE MADE...

AND 2 SIDES IN REFERENCE TO WHICH PROCEDURES SHOULD BE FOLLOWED, WHEN THERE IS NO CONSENSUS.

SOME PHYSICIANS AT THE HOSPITAL DISAGREED WITH THE NEGATIVE OPINION OF THEIR COLLEAGUES AND THE DECISION OF THE PARENTS. AND THEY WENT INTO COURT TO SEEK AN INJUNCTION TO PREVENT THE PARENTS' DECISION FROM BEING CARRIED OUT. INSTEAD, THEY WANTED THE COURT TO REQUIRE THAT "BABY DOE" BE GIVEN SOME NOURISHMENT AND SOME MEDICAL CARE. THESE PHYSICIANS USED AS THE BASIS OF THEIR COMPLAINT AN INDIANA LAW ON CHILD ABUSE AND NEGLECT.

A CIRCUIT JUDGE HEARD TESTIMONY FROM BOTH SIDES -- EVEN HELD A LONG HEARING IN THE HOSPITAL ITSELF -- AND THEN RULED AGAINST THE PHYSICIANS. NO INJUNCTION WAS ORDERED AND SO, IN EFFECT, THE PARENTS WON THAT CASE.

BUT A SECOND CASE WAS BEGUN IN THE COUNTY PROSECUTOR'S OFFICE. TECHNICALLY, THIS WAS A PETITION TO THE COURT ENTERED ON BEHALF OF A CHILD ALLEGED TO BE THE VICTIM OF ABUSE OR NEGLECT.

THESE TWO CASES WERE IN THE JUDICIAL STREAM IN INDIANA, BEING APPEALED UP THE LADDER OF THE COURT SYSTEM. HOWEVER, ON APRIL 15, SEVEN DAYS AFTER HE HAD BEEN BORN, "BABY DOE" DIED AND APPEALS IN BOTH CASES WERE MOOTED. HENCE, EXCEPT FOR THAT FIRST HEARING IN THE COUNTY COURT, THE SUBSTANCE OF THE "BABY DOE" ISSUE HAS NEVER BEEN THOROUGHLY ADJUDICATED...IN INDIANA, IN WASHINGTON, IN CHICAGO...ANYWHERE.

IT'S IMPORTANT TO REVIEW THIS INFORMATION BECAUSE ALL THE ELEMENTS OF ANY "BABY DOE" CONTROVERSY WERE RIGHT THERE IN THE ORIGINAL CASE. AND FOR THE NEXT SEVERAL MINUTES I WANT TO GO OVER THEM FOR YOU, FROM MY PERSPECTIVE...AS A SURGEON...AS A PHYSICIAN...AND AS SURGEON GENERAL.

FIRST, LET'S LOOK AT THE MEDICAL SIDE OF THIS ISSUE.

THE INITIAL DIAGNOSIS OF "BABY DOE" BY SOME OF THE MEDICAL STAFF RAISED SOME EYEBROWS. WHILE IT IS TRUE THAT SURGERY TO REPAIR ESOPHAGEAL ATRESIA IN A NEWBORN CAN BE DIFFICULT AND TRICKY, IT IS ALSO TRUE THAT THE SUCCESS RATE IS VERY HIGH, AS I HAVE ALREADY INDICATED. I WOULD SAY THAT THE SURGICAL COMMUNITY HAD SOME LEGITIMATE QUESTIONS ABOUT THE VALIDITY OF THE OBSTETRICIAN'S COUNSEL TO THE PARENTS OF "BABY DOE."

AND WE HAD TO QUESTION THE PHYSICIAN'S COUNSEL, ALSO. WE ARE GIVEN TO UNDERSTAND THAT THAT PERSON HAD INDICATED TO THE PARENTS THAT THE QUALITY OF "BABY DOE'S" FUTURE LIFE WOULD NOT BE VERY GOOD. AND THIS, TOO, RAISED SOME EYEBROWS.

THE FACT IS THAT THERE IS SIMPLY NO WAY THAT A PHYSICIAN CAN PREDICT WITH ANY ACCURACY AT ALL JUST WHAT THE "QUALITY OF LIFE" WILL BE FOR A CHILD BORN WITH DOWN SYNDROME. THE SCALE OF RETARDATION CAN PASS FROM MILD TO SEVERE. AND AT EVERY POINT ON THAT SCALE, THE "QUALITY OF LIFE" IS AFFECTED BY THE CHILD'S FAMILY, THE RESPONSE OF THE COMMUNITY, AND THE KIND AND DEGREE OF MEDICAL AND HEALTH SERVICES THAT ARE AVAILABLE.

SOME PEOPLE IN THE CHILD'S HOME TOWN AS WELL AS SOME OF US IN WASHINGTON, THOUGHT THAT MAYBE THE PARENTS HADN'T BEEN GIVEN TOTALLY ACCURATE, BIAS-FREE, PROFESSIONALLY CONSERVATIVE INFORMATION ABOUT THE CONDITION OF THEIR NEW BABY BOY.



"BABY DOE'S" MEDICAL RECORDS WERE SEALED BY THE COURTS. NEVERTHELESS, I WAS ASKED TO DO SOME LONG-DISTANCE HYPOTHESIZING ABOUT "BABY DOE'S" CHANCES. I REFUSED. I BELIEVED THEN -- AND I GREW TO BELIEVE IT MORE INTENSELY LATER -- THAT THESE KINDS OF PROBLEMS CAN BE ANSWERED BEST BY RESPONSIBLE PEOPLE WHO ARE RIGHT THERE ON THE SCENE.

"BABY DOE" DIED ON APRIL 15, 1982, A WEEK AFTER HIS BIRTH. HIS DEATH CERTIFICATE INDICATED "MULTIPLE CONGENITAL DEFECTS." BUT WHAT DID THAT MEAN?:

- o WAS THERE AN IRREPARABLE HEART DEFECT? NEARLY HALF OF ALL DOWN SYNDROME INFANTS ARE BORN WITH CONGENITAL HEART DISEASE AND THE MORTALITY RATES FOR SUCH INFANTS ARE VERY HIGH.

- o WAS THERE IRREVERSIBLE BRAIN DAMAGE?
  
- o OR WERE THE "MULTIPLE DEFECTS" ONLY THE 2 I HAVE ALREADY DISCUSSED...THAT IS, DOWN SYNDROME AND ESOPHAGEAL ATRESIA?

IN ANY CASE, THE PUBLIC DIDN'T HAVE ANY OF THIS INFORMATION BETWEEN APRIL 8 AND APRIL 15, 1982. WE DIDN'T HAVE IT THEN...AND WE STILL DON'T HAVE IT NOW.

THE MEDICAL PROFESSION WAS DOUBLY FRUSTRATED IN THIS CASE. FIRST, OF COURSE, THERE WAS THE LACK OF THE MEDICAL DATA. WE WERE THEORIZING IN THE DARK, WHICH IS REALLY ANATHEMA TO PHYSICIANS.

THE SECOND FRUSTRATION ALSO GOES RIGHT TO THE CORE OF CONTEMPORARY MEDICAL PRACTICE...FOR BETTER OR FOR WORSE. DEVELOPMENTS OF THE PAST 20 YEARS HAVE SO GREATLY EXPANDED THE RANGE OF CURATIVE MEDICINE, THAT PHYSICIANS SIMPLY CANNOT ABIDE CONFRONTING A CASE THAT CANNOT BE CURED.

BUT "BABY DOE" WAS THAT KIND OF CASE. "BABY DOE" REMINDED US THAT FOR HIM...AS FOR MANY OF OUR PATIENTS...WE HAVE NO CURES. BUT THE "BABY DOES" OF THIS WORLD NEED SOMETHING ELSE THAT'S JUST AS VALUABLE AS A MAGICAL MEDICAL CURE. THEY NEED A LOT OF GENUINE CARE. THEY STILL NEED US IN OUR ROLE AS PEOPLE, EVEN THOUGH WE CAN'T DO VERY MUCH FOR THEM IN OUR ROLE AS PHYSICIANS.

THAT'S AN IMPORTANT MESSAGE. IT'S ALSO A DEMANDING MESSAGE. IT DEMANDS THAT WE LAY ASIDE OUR MEDICAL TEXTS AND, INSTEAD, SIT DOWN AND WORK THROUGH THOSE QUESTIONS AND ANSWERS THAT ARE SPUN OUT OF THE DEPTHS OF OUR CONSCIENCE...NOT OUT OF MEDICAL TEXTS.

IN MY PEDIATRIC SURGICAL PRACTICE I HAD COME UPON VARIATIONS OF THIS KIND OF SITUATION BEFORE. OFTEN...ENOUGH SO THAT THE EXPERIENCE WAS ENGRAVED IN MY MIND FOREVER;

A TRAGICALLY DISABLED CHILD...PARENTS WHO ARE CONFUSED, ANGRY, GRIEVING...A DIVIDED MEDICAL STAFF. WHAT THEN?

MY CONSIDERED JUDGMENT -- WORKED OUT OVER SOME YEARS -- TELLS ME THAT WE HAVE A CLEAR LEGAL AND A CRYSTAL-CLEAR MORAL RESPONSIBILITY TOWARD THESE PATIENTS AND THEIR FAMILIES:

WE OUGHT TO DO THOSE THINGS THAT WILL GIVE A PERSON ALL THE LIFE TO WHICH HE OR SHE IS ENTITLED, BUT NOT DO ANYTHING THAT WOULD VAINLY EXTEND THAT PERSON'S ACT OF DYING.

WITH "BABY DOE," ORAL INTAKE WAS IMPOSSIBLE BECAUSE OF THE ESOPHAGEAL LESION. PARENTERAL ALIMENTATION WOULD NOT SOLVE THE PROBLEM -- EVEN TEMPORARILY -- BECAUSE PULMONARY ASPIRATION OF PHARYNGEAL SECRETIONS AND OF GASTRIC JUICE THROUGH THE TRACHEO-ESOPHAGEAL FISTULA WOULD BE LETHAL. IF ALL WE KNEW ABOUT THE CASE WAS WHAT THE PRESS REPORTED, THEN I WOULD HAVE TO SAY THAT "BABY DOE" -- AT THE VERY LEAST -- DESERVED SURGERY FOR THE LESION. IT COULD HAVE BEEN A LIFE-SUSTAINING PROCEDURE AND WOULD NOT HAVE MERELY PROLONGED THE ACT OF DYING. BUT AGAIN, I HAVE TO SAY THAT WE DID NOT HAVE THE COMPLETE MEDICAL RECORD.

BUT "BABY DOE" DOES NOT FIT NEATLY INTO ANY OF THE LEGAL OR MEDICAL OR ETHICAL PIGEONHOLES WE HAVE ALL SO CAREFULLY CONSTRUCTED FOR OURSELVES OVER TIME. THIS WAS NOT A STRAIGHTFORWARD CASE OF CHILD ABUSE AND NEGLECT, IN WHICH A NORMAL, HEALTHY CHILD HAD BECOME THE VICTIM OF PARENTAL VIOLENCE.

NO ONE DID ANYTHING "VIOLENT" TO "BABY DOE." TRUE...NO ONE MOVED TO HELP HIM, BUT NO ONE LIFTED A FINGER AGAINST HIM EITHER. HE WASN'T DRIVEN OUT OF THE HOUSE INTO THE COLD, BLACK NIGHT, BUT NEITHER WAS HE THE NORMAL, HEALTHY CHILD THAT PEOPLE EASILY SEE IN THEIR MIND'S EYE.

THE KEY TO THIS CASE, THEN, WAS THE CHILD'S HANDICAPPED CONDITION. THIS IS WHAT MADE IT NEWSWORTHY...WHAT MADE THE CIRCUMSTANCES PARTICULARLY TROUBLING...AND WHAT STIMULATED A NUMBER OF PEOPLE IN INDIANA, ELSEWHERE IN THE COUNTRY, AND IN WASHINGTON TO THINK ABOUT "BABY DOE" AS A VICTIM OF DISCRIMINATION, INSTEAD OF -- OR IN ADDITION TO -- BEING A VICTIM OF ABUSE AND NEGLECT.

EVEN BEFORE "BABY DOE'S" SHORT, ONE-WEEK LIFETIME HAD ENDED, MANY PEOPLE WERE BEGINNING TO ASK IF THE CARE BEING GIVEN "BABY DOE" WAS THE KIND OF CARE ANY BABY WITH ESOPHAGEAL ATRESIA WOULD RECEIVE? THE CANDID OPINION WAS..."PROBABLY NOT."

THE ASSOCIATED DOWN SYNDROME WAS, THEREFORE, EXTREMELY SIGNIFICANT. IF "BABY DOE" HAD ONLY HAD DOWN SYNDROME, HE WOULD HAVE BEEN NOURISHED AND CARED FOR. IF HE HAD ONLY HAD ESOPHAGEAL ATRESIA, HE WOULD HAVE BEEN OPERATED ON AND CURED. YOU DON'T HAVE TO BE POSITIVE ABOUT ANY OF THIS, OF COURSE. LAW AND ETHICS ONLY REQUIRE THAT THERE BE A REASONABLE SUSPICION THAT SUCH IS THE CASE. AND THERE WAS.

HENCE, THE "BABY DOE" ARGUMENT BEGAN TO CENTER AROUND WHAT WE CALL IN THE UNITED STATES, SECTION 504 OF THE REHABILITATION ACT OF 1973, OR PUBLIC LAW 93-112. THAT SECTION SAYS THAT "NO OTHERWISE QUALIFIED HANDICAPPED INDIVIDUAL...SHALL, SOLELY BY REASON OF HIS HANDICAP, BE EXCLUDED FROM THE PARTICIPATION IN, BE DENIED THE BENEFITS OF, OR BE SUBJECTED TO DISCRIMINATION UNDER ANY PROGRAM OR ACTIVITY RECEIVING FEDERAL FINANCIAL ASSISTANCE."

THIS IS ALMOST IDENTICAL TO THE LANGUAGE OF TITLE VI OF THE CIVIL RIGHTS ACT OF 1964 AND OF TITLE IX OF THE EDUCATION AMENDMENTS OF 1972. THOSE TWO LAWS FORBID ANYONE USING FEDERAL FUNDS FROM DENYING BENEFITS OR SERVICES TO A BLACK PERSON BECAUSE HE OR SHE IS BLACK...OR A HISPANIC PERSON...OR AN ASIAN...OR AN ELDERLY PERSON...OR A WOMAN.

LIKE MOST MAJOR HOSPITALS IN THE COUNTRY, THE HOSPITAL WHERE THIS CHILD WAS BORN DID AND DOES RECEIVE FEDERAL ASSISTANCE AND, THEREFORE, MUST CONDUCT ITS AFFAIRS ACCORDING TO A NUMBER OF FEDERAL LAWS, INCLUDING THOSE I MENTIONED.

BUT WE WERE ALL AWARE OF A LARGER, UNDERLYING QUESTION OF LAW THAT CAME UP EARLY IN THE HISTORY OF "BABY DOE." BRIEFLY STATED, IT IS THIS: DOES THE STATE HAVE ANY BUSINESS AT ALL TO STEP INTO A MATTER AFFECTING A NEWBORN CHILD AND GO OVER THE HEADS, SO TO SPEAK, OF THE PARENTS?



WHEN THE "BABY DOE" CASE FIRST HIT THE NEWSPAPERS, A NUMBER OF PEOPLE SAID THE GOVERNMENT "HAD NO RIGHT" TO INTERFERE IN A MATTER THAT WAS THE RESPONSIBILITY ONLY OF THE PARENTS AND OF THE ATTENDING PHYSICIANS. SOMEHOW, OUR NATIONAL EXPERIENCE WITH TRUANCY LAWS AND CHILD ABUSE LAWS AND IMMUNIZATION LAWS WAS IRRELEVANT. AND ANYWAY, THOSE LAWS PROTECT CHILDREN WHO ARE NO LONGER INFANTS.

BUT I WOULD RESPOND BY NOTING THAT THERE IS NO CONSTITUTIONAL DEFINITION OF HOW OLD SOMEONE HAS TO BE IN ORDER TO RECEIVE THE PROTECTION OF THE STATE. THERE IS NO MINIMUM-AGE REQUIREMENT FOR NATIVE-BORN CITIZENSHIP. FOR EXAMPLE, AN AMERICAN-BORN CHILD DOES NOT HAVE TO REMAIN IN THE UNITED STATES FOR A MONTH...OR TWO WEEKS...OR EVEN FOR ONE HOUR IN ORDER TO QUALIFY FOR A SOCIAL SECURITY NUMBER AND A PASSPORT. THE CHILD MERELY HAS TO BE "BORN" AS AN AMERICAN. HE/SHE CAN EVEN BE PRESIDENT.

THE REGULATIONS REGARDING "BABY DOE" WRITTEN BY OUR DEPARTMENT WERE CHALLENGED IN COURT AND STRUCK DOWN. I TRIED AGAIN AND THIS TIME WE SUCCEEDED WITH A FINAL RULE THAT WAS PROTECTIVE OF CHILDREN...CONDUCTIVE TO BETTER PATIENT CARE...AND NOT BURDENSOME TO THOSE WHO CARE FOR NEWBORNS.

MEANWHILE, THE U.S. CONGRESS TOOK THIS NEW VERSION AND, IN 1985, WROTE NEW LEGISLATION BASED UPON IT. THE CONGRESS CALLED THE "BABY DOE" SITUATION A CASE OF "MEDICAL NEGLIGENCE." IT REQUIRED NEW PROCEDURES IN HOSPITALS TO IDENTIFY AND PREVENT SUCH "MEDICAL NEGLIGENCE" FROM OCCURRING.

THE LAW WENT INTO EFFECT THREE YEARS TO THE DAY AFTER "BABY DOE" DIED. A RECENT TELEPHONE SURVEY OF HOSPITALS IN ALL 50 STATES SEEMED TO INDICATE THAT THE LAW WAS BEING OBSERVED AND THE LIVES OF MANY CHILDREN HAVE BEEN SAVED.

THE "BABY DOE" EXPERIENCE WAS A HARD LESSON FOR ME. IT TAUGHT ME ONCE AGAIN THAT CONTEMPORARY SOCIETY, WITH ALL ITS TECHNOLOGY AND SOPHISTICATION, IS STILL SLOWLY WORKING OUT ITS RESPONSES TO THE MOST BASIC QUESTIONS OF ETHICS AND MORALITY.

HENCE, IF YOU ARE COMMITTED TO SAVING LIVES THAT ARE PUT AT RISK BECAUSE OF ETHICAL CONFLICTS, YOU HAVE TO BE PREPARED TO NEGOTIATE HARD AND FIGHT HARD FOR EACH LIFE.

AND THAT BATTLE IS VERY DIFFICULT, BECAUSE YOUR ADVERSARIES ARE NOT MONSTERS...THEY ARE JUST AS HUMAN AS YOU ARE.

I SOMETIMES THINK THAT, IF THE "BABY DOES" OF THIS WORLD WERE 25 YEARS OLD, THEY WOULD HAVE A NATIONAL ADVOCACY ORGANIZATION AND A STRONG CONGRESSIONAL LOBBY AND MOST OF OUR DISCUSSION TODAY WOULD BE QUITE ACADEMIC. BUT UNFORTUNATELY, THESE BABIES ARE TOO SMALL, TOO WEAK, AND TOO POOR.

THESE EXPERIENCES, AS IMPORTANT AS THEY WERE, SEEM IN RETROSPECT TO HAVE BEEN A KIND OF TRAINING FOR THE ISSUE THAT OCCUPIES VIRTUALLY ALL MY WAKING HOURS THESE DAYS.

IT IS THE ISSUE OF AIDS. AND, AGAIN, CHILDREN ARE FOR ME AT THE HEART OF IT.

VIRTUALLY ALL OUR ATTENTION IN THE MATTER OF AIDS HAS BEEN FOCUSED ON THE TWO MAJOR GROUPS OF AIDS VICTIMS: HOMOSEXUALS AND BISEXUAL MALES, WHO COMPRISE TWO-THIRDS OF ALL AIDS CASES, AND DRUG ADDICTS WHO USE CONTAMINATED NEEDLES, WHO COMPRISE A FOURTH OF ALL AIDS VICTIMS.

THE TOTAL NUMBER OF AIDS CASES IN OUR COUNTRY SO FAR HAS NOW SURPASSED 42,000. OF THAT NUMBER, ALMOST 600 HAVE BEEN CHILDREN UNDER THE AGE OF 13. THE GREAT MAJORITY OF THEM HAD THE DISEASE AT BIRTH, BUT A HUNDRED OR SO ARE EITHER HEMOPHILIACS OR RECEIVED THE VIRUS IN TRANSFUSED BLOOD OR BLOOD PRODUCTS SOMETIME BEFORE 1985.

BY 1991 WE ESTIMATE THAT AS MANY AS 3,000 CHILDREN WILL HAVE HAD AIDS.

WHAT IS HAPPENING TO THESE CHILDREN?

THE MOST CELEBRATED CASE IS THAT OF THE THREE RAY BOYS IN ARCADIA, FLORIDA. THEY WERE EXCLUDED FROM THE LOCAL ELEMENTARY SCHOOL THERE AND, BRIEFLY, IN NEIGHBORING ALABAMA AS WELL.

THE DISCRIMINATION HAS ALSO SPREAD TO THEIR SISTER, WHO WAS INITIALLY EXCLUDED FROM SCHOOL AS WELL, AND TO THEIR FATHER, WHO HAS HAD TO LEAVE HIS JOB.

THE LOCAL BARBER WOULD NOT CUT THEIR HAIR. THEIR CHURCH AND ITS PRIEST ASKED THAT THE RAY FAMILY NO LONGER ATTEND.

THERE ARE MANY INSTANCES OF OTHER HEMOPHILIAC CHILDREN WHO ARE RECEIVED BY THEIR NEIGHBORS WITH THE SAME KIND OF FEAR AND HATE AS LEPERS WERE IN THE MIDDLE AGES.

A WORSE SITUATION IN MANY PUBLIC HEALTH RESPECTS EXISTS AMONG THE CHILDREN BORN WITH AIDS.

THEY ARE BORN TO DRUG ABUSING WOMEN OR TO THE SEXUAL PARTNERS OF DRUG ABUSING MEN. 81% ARE BLACK; ALMOST ALL THE REST ARE HISPANIC.

MOST OF THEM ARE ABANDONED BY THEIR MOTHERS...LEFT TO LIVE OR DIE IN THE HOSPITAL NURSERY...ATTENDED BY PEDIATRIC NURSES WHO NEVER IMAGINED THAT SUCH TRAGEDY WOULD BE THE DAILY STUFF OF THEIR PROFESSIONAL LIVES.

MOST OF THE INFANTS GROW OLD ENOUGH AND ARE ASYMPTOMATIC ENOUGH TO BE MOVED OUT OF THE HOSPITAL AND PLACED IN FOSTER HOMES.

BUT THAT ISN'T EASY BECAUSE THE STIGMA OF THE DIAGNOSIS AND THE METHODOLOGY OF THE TRANSMISSION OF THE DISEASE ARE WIDELY HELD BY THOSE USUALLY AVAILABLE TO PROVIDE FOSTER CARE.

IN NEW YORK CITY, WHICH HAS THE LARGEST NUMBER OF HOMELESS OLDER CHILDREN WITH AIDS, A COMPLEX SYSTEM OF TOTAL CONFIDENTIALITY IS MAINTAINED, SO THAT WHEN AN AIDS CHILD APPEARS IN SCHOOL, NEITHER THE PRINCIPAL, NOR THE TEACHERS, NOR THE STUDENTS, NOR ANYONE ELSE IN THE SCHOOL OR THE NEIGHBORHOOD KNOWS IF HE OR SHE IS AN AIDS CHILD OR NOT.

WE'VE GOTTEN THIS FAR. BUT WE'RE NOT SURE WHAT LIES AHEAD FOR THESE CHILDREN...OR FOR THE SOCIETY THAT SUPPORTS THEM. CLEARLY THEY ARE MORE THAN JUST "WARDS OF THE STATE." NEW YORK CITY CAN TRY TO MAKE THEIR LIVES AS NORMAL AS POSSIBLE, YET THESE CHILDREN CANNOT ENGAGE IN ANY ACTIVITIES -- APPROVED OR UNAPPROVED -- IN WHICH THEIR BLOOD MAY MIX WITH ANOTHER'S.



WHAT HAPPENS WHEN THEY ENTER AND PASS THROUGH PUBERTY? IT'S NOT TOO MANY YEARS AWAY. WE KNOW THAT THE AIDS VIRUS CAN INCUBATE THAT LONG AND WE WON'T HAVE A VACCINE BY THEN.

SO WHAT KIND OF "WARD OF THE STATE" DOES SUCH A CHILD BECOME?

WE REJECT QUARANTINE FOR PEOPLE WITH AIDS. IT IS NOT A SOLUTION OF ANY SORT. RATHER, IT IS ANOTHER AND EVEN LARGER PROBLEM THAN THE DISEASE ITSELF.

YET, THESE CHILDREN ARE ALREADY LIVING LIVES OF SEPARATENESS TO A GREAT DEGREE. HOW MUCH MORE CAN THEY -- AND CAN SOCIETY -- ENDURE?

I WAS ABLE TO BRING MY OTHER LITTLE STORIES TO SOME KIND OF CLOSE. BUT THIS ONE IS STILL AN OPEN BOOK.

AFTER ALL THE OTHER ISSUES SURROUNDING AIDS ARE THRASHED OUT AND WE EACH RETURN TO OUR APPOINTED TASKS, THE SHADOW OF THESE CHILDREN GROWS LONGER ON THE WALL BEHIND US.

THIS IS NOT A UNIQUE, "AMERICAN" PROBLEM. BUT, IN OUR UNIQUELY AMERICAN WAY, WE ARE PERHAPS THE FIRST TO TALK OPENLY ABOUT IT. AND WE MUST...WE ALL MUST...BECAUSE THESE CHILDREN WITH AIDS WILL SOON BE IN EVERY COUNTRY ASKING FOR THE THING THAT ALL CHILDREN WANT: A FUTURE.

AND, FOR THE FIRST TIME, I AM FORCED TO ADMIT TO THESE CHILDREN THAT...I DON'T BELIEVE THERE IS ONE.

THANK YOU.