THE HANDICAPPED CHILD AND HIS FAMILY

C. Everett Koop, M.D., ScD.
Surgeon-in-Chief
The Children's Hospital of Philadelphia
Professor of Pediatric Surgery and Pediatrics
University of Pennsylvania School of Medicine

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IN ADDRESSING AN AUDIENCE ON THE SUBJECT "THE HANDICAPPED CHILD AND HIS FAMILY", IT IS EASIER THAN IT OTHERWISE MIGHT BE IN KNOWING THAT I AM TALKING TO A GROUP OF PHYSICIANS WHO HAVE ESPOUSED CHRISTIAN VALUES BOTH REGARDING THE SANCTITY OF LIFE AND THE INTEGRITY OF THE FAMILY. THEREFORE, WHAT I HAVE TO SAY WILL BE BASED UPON FUNDAMENTAL PREMISES ON WHICH WE WILL ASSUME WE AGREE: FIRST, THAT THE FAMILY WAS INSTITUTED OF GOD AS THE BASIC MODULE AROUND WHICH SOCIETY AND THEREFORE CIVILIZATION IS BUILT; SECONDLY, THAT EACH NEWBORN INFANT PERFECT OR DEFORMED IS A HUMAN BEING WITH UNIQUE PRECIOUSNESS BECAUSE HE WAS CREATED IN THE IMAGE OF GOD.

WHEN IT COMES TO AN ASSESSMENT OF THE PRESENT SITUATION IN REFERENCE TO HANDICAPPED CHILDREN, I AM ~~IN THE FIELD~~ WITH WHICH I HAVE INTIMATE FAMILIARITY. AS MANY OF YOU KNOW, I HAVE SPENT THE MAJOR PART OF THE THIRTY-FOUR (34) YEARS I HAVE BEEN IN THE ACTIVE PRACTICE OF PEDIATRIC SURGERY BEING CONCERNED PRIMARILY WITH THE SURGERY OF THE NEWBORN IN AN ATTEMPT TO CORRECT THOSE CONGENITAL DEFECTS INCOMPATIBLE WITH LIFE BUT AMENABLE TO SURGICAL CORRECTION AND TO CARRY OUT, IN THE LONG AND THE SHORT TERM, THOSE REHABILITATIVE EFFORTS WHICH RESTORE A CHILD TO SOCIETY, PERHAPS NOT PRISTINE IN FORM AND FUNCTION, BUT LOVED AND LOVING, INNOVATIVE AND CREATIVE, AND WITH A ZEST FOR LIFE.--THE OLD FASHIONED LIFE,--THAT I FIND LACKING IN THE

CYNICAL MANIPULATED, SO FREQUENTLY TO-BE-PITIED, NORMAL CHILDREN OF TODAY.

LET ME REVIEW BRIEFLY THE LIFE HISTORY OF THE DEVELOPMENT OF ONE OF THE TRAGIC PROBLEMS THAT WE ARE HERE TO DISCUSS TODAY. A FAMILY HAVING ENDURED A PREGNANCY LOOKS FORWARD TO THE BIRTH OF THEIR CHILD AND IN THEIR MIND'S EYE HE RESEMBLES NOTHING SO MUCH AS THE ROSY CHEEKED, BLOND HAIRED BABY SEEN IN THE GERBER'S BABY FOOD ADVERTISEMENTS. INSTEAD THE YOUNGSTER IS BORN WITH A VISIBLE DEFECT WHICH MAY HAVE NOT ONLY PHYSICALLY HANDICAPPING POTENTIAL BUT PERHAPS EVEN MENTAL RETARDATION. THE WHOLE EXPECTED WORLD HAS CRASHED DOWN AROUND THE FAMILY. IT IS EVEN POSSIBLE THAT THE MOTHER AWAKES FROM ANESTHESIA TO FIND THAT HER LONG EXPECTED CHERUB IS FAR LESS CHERUBIC THAN ANTICIPATED AND THAT HE HAS BEEN WHISKED OFF TO ANOTHER HOSPITAL WHICH TO HER CAN ONLY BE HOSTILE AND WORSE THAN THAT, THE SUPPORT SHE WOULD LIKE TO HAVE FROM HER HUSBAND IS LACKING BECAUSE HE HAS ACCOMPANIED THE BABY TO ITS NEW ENVIRONMENT.

THIS DOES NOT MEAN THAT THE FAMILY SHOULD NOT BE TOLD IMMEDIATELY OF THEIR PROBLEM BUT IT DOES INDICATE THAT THE MANNER IN WHICH THEY ARE TOLD HAS TO BE POSITIVE AND HAVE BUILT INTO IT EVERY SINGLE POSSIBLE SUPPORTIVE SYSTEM AND PROMISE THAT IT IS POSSIBLE FOR THE PRIMARY PHYSICIAN TO ACCOMPLISH; WHETHER HE BE PEDIATRICIAN, OBSTETRICIAN OR FAMILY PRACTITIONER.

WHAT DO I MEAN BY BEING SUPPORTIVE? I AM ALWAYS REALISTIC AND IN REFERENCE TO THE DEFORMITY IN QUESTION TEND TO BE PESSIMISTIC IF ANYTHING SO THAT IF THINGS WORK OUT BETTER THAN MY EXPERIENCE WOULD INDICATE, THEN THAT IS A POSITIVE DIVIDEND FOR THE FAMILY RATHER THAN A DISAPPOINTING DESCENT TO REALITY. ON THE OTHER HAND, AS THE PEDIATRIC SURGEON INTO WHOSE HANDS THE PROBLEM HAS BEEN DELIVERED FOR AT LEAST IMMEDIATE ATTENTION, I FEEL CERTAIN RESPONSIBILITIES AND I FEEL THEM DEEPLY. I RECOGNIZE THE FAMILY'S TENDENCY TO BELIEVE THAT THEY ARE RESPONSIBLE FOR THE DEFECT, PERHAPS GUILTY ABOUT IT, AND CERTAINLY ANGRY AND FRUSTRATED INTO THE BARGAIN. I FEEL I MUST BE AUTHORITATIVE, TRANSMIT A SENSE OF COMPETENCE BASED UPON EXPERIENCE, AND GIVE THE IMPRESSION THAT HAVING BEEN THROUGH THIS SITUATION BEFORE WITH OTHER FAMILIES AND THEIR DEFECTIVE CHILD THAT I KNOW MY WAY AROUND THE MORASS OF PRIVATE AND GOVERNMENT AGENCIES THAT CAN GIVE AID. I WILL ACT AS THE PILOT THROUGH THESE TROUBLED WATERS TO SEE THAT EVERY CONCEIVABLE SUPPORTIVE EFFORT THAT IS AVAILABLE IS BROUGHT TO BEAR UPON THE EVENTUAL OUTCOME IN THIS SPECIFIC INSTANCE.

IT HAS BEEN MY CUSTOM FOR SEVERAL DECADES TO PRACTICE THIS KIND OF SUPPORTIVE THERAPY. I TELEPHONE THE MOTHER IN HER LYING-IN HOSPITAL AND ASSURE HER OF ALL THE THINGS THAT

I THINK WILL BE SUPPORTIVE. I REPEAT THESE THINGS TO HER HUSBAND AND ASK HIM TO GO HOME AND TRANSMIT THEM TO HIS WIFE. WE HAVE A BUILT IN NURSING AND SOCIAL SERVICE COMMUNICATION SYSTEM THAT UNDERLINES WHAT I HAVE TRIED TO DO PERSONALLY. I MIGHT ALSO ADD THAT MY COLLEAGUES INVOLVED IN THE SAME TYPE OF SURGICAL ENDEAVOR PRACTICE MEDICINE IN THIS SAME WAY.

CONTRARY TO WHAT THE LOCAL PROTECTIVE OBSTETRICIAN USUALLY WANTS TO DO, I INSIST THAT THE MOTHER COME TO SEE HER CHILD AS SOON AS SHE POSSIBLY CAN AND EVEN THOUGH IT MAY BE BANDAGED, INTUBATED, MONITORED AND BEING FED WITH A HYPERALIMENTATION LINE, I WANT HER TO TOUCH HER CHILD AND IF POSSIBLE EVEN HOLD IT AND CUDDLE IT TO ESTABLISH AS BEST WE CAN THOSE BONDS WHICH SHOULD HAVE BEEN ESTABLISHED EARLIER. IF I HAVE ANYTHING TO DO WITH IT, THIS CHILD IS GOING TO MAKE IT BUT HE IS GOING TO MAKE IT EVER SO MUCH BETTER SOCIALLY AND EMOTIONALLY IF HE CAN MAKE IT IN HIS FAMILY.

I READ CONSTANTLY ABOUT THE PROBLEMS THAT PARENTS FACE IN THESE SITUATIONS: HOW IT IS LIKE LOSING A CHILD, HOW THEY EXPERIENCE A PROLONGED PERIOD OF GRIEF, HOW THEY FEEL ISOLATED FROM SOCIETY, HOW THEY SHARE GUILT AND SHAME AND INDEED EVENTUALLY MIGHT BECOME PHYSICALLY ILL AND MENTALLY DISTURBED.

IT HAS BEEN MY LIFE-LONG EXPERIENCE THAT THE SUPPORT THAT I HAVE JUST MENTIONED ACTUALLY PREVENTS THESE CATASTROPHES. WHEN IT TAKES SO LITTLE EFFORT AND IS SO REWARDING, I CANNOT SEE HOW THERE CAN BE ANY ARGUMENT ABOUT HOW THE FAMILY SHOULD BE APPROACHED.

NOW I REALIZE THAT MY APPROACH IS VERY OLD FASHIONED. I RECENTLY CAME INTO A SITUATION IN A NEARBY HOSPITAL THIRD HAND. THE OPENING GAMBIT ON THE PART OF THE NEONATOLOGIST TO THE PARENTS OF A MONGOLOID CHILD WITH INTESTINAL OBSTRUCTION WAS SOMETHING LIKE THIS: "YOUR CHILD HAS DOWN'S SYNDROME WHICH MEANS HE WILL BE SEVERELY, MENTALLY RETARDED. HE ALSO HAS A SURGICAL PROBLEM OF INTESTINAL OBSTRUCTION WHICH WILL KILL HIM IF UNCORRECTED. YOU HAVE SEVERAL OPTIONS IN TREATMENT, THE FIRST OF WHICH IS TO DO NOTHING IN WHICH CASE YOU WILL NOT HAVE TO FACE EITHER OF THE PROBLEMS THAT I HAVE JUST OUTLINED."

THAT FAMILY OPTED NOT TO HAVE THEIR CHILD OPERATED UPON AND THEN FOOLISHLY THAT NEONATOLOGIST ASKED FOR A SURGICAL CONSULTATION BY ONE OF MY SURGICAL COLLEAGUES. THIS IMMEDIATELY PROVIDED AN ANTAGONISTIC SUGGESTED FORM OF MANAGEMENT AND AFTER AN UNBELIEVABLE NUMBER OF LEGAL, SOCIAL AND PERSONAL MANEUVERS WHICH I WILL NOT GO INTO, THE CHILD WAS OPERATED UPON (IT HAD MALROTATION OF THE COLON; NOT DUODENAL ATRESIA AND THEREFORE THE SURGERY WAS MORE

URGENTLY INDICATED THAN USUAL), RECOVERED WELL, WAS ADOPTED BY A MARVELOUS LADY WHO HAD RECENTLY LOST A CHILD AND HAS ENTERED WHAT I THINK WILL BE A LIFELONG LOVING SUPPORTIVE RELATIONSHIP.

NOW, I AM ABSOLUTELY CONVINCED THAT THE PARENTS WHO OPTED TO LET THEIR CHILD DIE AND ONLY CONSENTED TO ITS SURGERY WHEN IT WAS GUARANTEED THAT THEY WOULD NEVER HAVE TO BE CONCERNED WITH THE CHILD AGAIN WILL HAVE, IF NOT NOW, LATER THE GRIEF, THE GUILT, THE SHAME, THE PHYSICAL PROBLEMS AND EVEN THE MENTAL ABERRATIONS THAT COME WITH THE ABANDONMENT OF ONE'S FLESH AND BLOOD.

AS YOU MIGHT HAVE SUSPECTED, I DO NOT OFFER THE OPTION OF DEATH AS A FORM OF MANAGEMENT OF A CHILD WITH A CONGENITAL DEFECT. I CAN ALSO TELL YOU WITH COMPLETE CANDOR THAT NO FAMILY HAS EVER SAID TO ME EITHER BEFORE OR AFTER I HAVE PRESENTED THEM WITH A PROBLEM THAT THEY FACE THAT THEY WANTED THEIR CHILD TO BE LEFT UNATTENDED RATHER THAN TO FACE THE PROBLEMS OF RAISING A HANDICAPPED CHILD. I CANNOT HELP BUT THINK THAT THIS ALSO IS PART OF THE WAY THAT I APPROACH A PARENT. I NEVER PAUSE BETWEEN THE STATEMENT OF A HANDICAP, AND THE ASSURANCE OF MY SUPPORT IN EVERY CONCEIVABLE WAY POSSIBLE TO MAKE THIS COME OUT AS BEST IT CAN FOR THE FAMILY AND FOR THE CHILD.

MOST OF YOU KNOW THAT I AM ONE OF THE FEW PHYSICIANS IN THE COUNTRY WHO IS WILLING TO CALL THE NEGLECT OF CHILDREN WITH CONGENITAL DEFECTS INCOMPATIBLE WITH LIFE WHAT IT IS, INFANTICIDE, AND TO STAND BEFORE PROFESSIONAL AND LAY AUDIENCES ALIKE AND CONDEMN THIS PRACTICE AS HOMICIDE. AT THE PRESENT TIME IN THE UNITED STATES, MOST OF THE CHILDREN ON WHOM INFANTICIDE IS PRACTICED DIE FROM WHAT WILL EVENTUALLY BE CALLED PASSIVE EUTHANASIA AND THEIR LESIONS ARE EITHER SEPARATELY OR IN COMBINATION INCOMPATIBLE WITH LIFE IF UNTREATED.

SUCH IS NOT THE CASE IN THE UNITED KINGDOM, AS I AM SURE YOU KNOW WHERE THE CHIEF LESION UNDER DISCUSSION IS SPINA BIFIDA. SPINA BIFIDA IS NOT A LETHAL LESION BUT FAMILIES ARE TOLD THAT IT WILL BE LETHAL IN ABOUT THREE WEEKS. THE PROGNOSIS IS GUARANTEED BY OVERSEDATING THESE CHILDREN SO THAT THEY CANNOT TAKE THEIR FEEDINGS AND DIE OF STARVATION AND DEHYDRATION.

I RECENTLY TALKED TO ABOUT 7,000 PEOPLE IN SOME CITIES IN THE UNITED KINGDOM, WHILE SHOWING THE FILMS, "WHATEVER HAPPENED TO THE HUMAN RACE?". IN BIRMINGHAM AFTER PRESENTATION OF OUR FILM ON INFANTICIDE AND AFTER PROFESSOR ZACHARY AS OUTSPOKEN IN HIS COUNTRY AS I AM IN MINE HAD TALKED ON INFANTICIDE, A WOMAN ROSE TO ASK A QUESTION. THIS IS ESSENTIALLY WHAT SHE SAID: "I AM A GENERAL PRACTITIONER

IN THE NATIONAL HEALTH SERVICE. THREE YEARS AGO A DAUGHTER WAS BORN TO US WHO HAD SPINA BIFIDA AND I WAS TOLD THAT SHE WOULD DIE WITHIN THREE WEEKS. WHEN A NURSE TOLD ME THAT SHE WAS BEING STARVED TO DEATH, I SIGNED HER OUT OF THE HOSPITAL AGAINST ADVICE. SHE IS NOW A BRIGHT, ADORABLE THREE-YEAR-OLD GIRL WHO IS THE LIGHT OF OUR LIVES. HOWEVER, SHE HAS AN INCONTINENT BLADDER AND ORTHOPEDIC DEFORMITIES WHICH KEEP HER FROM WALKING. BUT BECAUSE I SIGNED HER OUT OF THE HOSPITAL AGAINST ADVICE AND BECAUSE SHE WAS INITIALLY CLASSIFIED AS NON-TREATABLE, THERE IS NO WAY THAT I CAN OBTAIN ANY UROLOGIC OR ORTHOPEDIC HELP FOR MY CHILD. AT MY OWN EXPENSE I AM KEEPING HER ON URINARY ANTIBIOTICS IN ORDER TO PROTECT HER KIDNEYS. WHAT CAN I DO?"

PROFESSOR ZACHARY TOLD HER THAT HER ONLY RECOURSE WAS TO SEEK PRIVATE CARE IN ENGLAND AND I TOLD HER THAT IF SHE WOULD GET THE CHILD TO PHILADELPHIA, WE WOULD EVENTUALLY SEND HER HOME WALKING IN CALIPERS, CONTROLLING HER URINE WITH AN ILEAL BLADDER AND SHE MIGHT EVEN BE THE SECOND LADY PRIME MINISTER OF GREAT BRITAIN.

MANY OF THE SO-CALLED SOCIAL ADVANCES THAT WE HAVE IN THIS COUNTRY HAVE COME ACROSS THE ATLANTIC FROM EAST TO WEST. IT TAKES ABOUT THIRTY YEARS FOR A NATIONAL HEALTH SERVICE CONCEPT TO CROSS THE OCEAN; IT TAKES ABOUT SIX YEARS FOR A CONCEPT LIKE ABORTION-ON-REQUEST TO CROSS THE OCEAN;

IT TOOK THE MINI-SKIRT ABOUT THIRTEEN (13) DAYS. I AM ABSOLUTELY CONVINCED THAT THE INFANTICIDE MENTALITY IN THIS COUNTRY WILL CONTINUE UNTIL IT ENCOMPASSES FAR MORE DEFECTS THAN IT DOES AT THE PRESENT TIME AND, OF COURSE, SPINA BIFIDA IS HIGH ON THE LIST. AS NEARLY AS I CAN ASSESS IN THIS COUNTRY ONLY ABOUT 5% OF CHILDREN WITH SPINA BIFIDA ARE NEGLECTED AND NOT TREATED WHEREAS IN GREAT BRITAIN THE NUMBER HAS NOW RISEN TO 75% OF THOSE BORN WITH THE DEFECT. VERY SHORTLY IT WILL BECOME A MOOT POINT BECAUSE OUR DEPARTMENT OF HHS HAS LAID ALL THE GROUNDWORK FOR ITS ALPHAFETOPROTEIN SCREENING WHICH WILL SUDDENLY BE INTRODUCED TO THIS COUNTRY IN ONE FELL SWOOP WITHOUT ANY PRELIMINARY DISCUSSION AND SPINA BIFIDA WILL RAPIDLY BECOME A THING OF THE PAST BECAUSE VERY FEW OF THESE BABIES WILL ESCAPE THE ABORTIONIST'S SUCTION TUBE.

I WOULD LIKE TO SUGGEST TO YOU SOME OF THE THINGS THAT HAPPEN IN THIS COUNTRY IN REFERENCE TO THE HANDICAPPED NEWBORN AND HIS FAMILY. FIRST OF ALL, HE ENCOUNTERS ONE OF FOUR KINDS OF PHYSICIANS. FIRST, SOMEONE WHO WILL ACT IN SUPPORT OF THE CHILD AND FAMILY AS I HAVE SUGGESTED THAT MY COLLEAGUES AND I DO. SECONDLY, THERE WILL BE THE PHYSICIAN WHO PRESENTS DEATH AS AN OPTION IN MANAGEMENT. THIRDLY, THERE WILL BE THE PHYSICIAN WHO SUGGESTS INSTITUTIONALIZATION FOR THE APPROPRIATE DIAGNOSIS, AND FINALLY

THERE WILL BE THE PHYSICIAN WHO WILL BE ONE OF THE PREVIOUS TWO BUT WHO BECOMES HOSTILE TO THE FAMILY BECAUSE HIS ADVICE HAS NOT BEEN TAKEN.

WHAT OF THE PARENTS? THEY HAVE SEVERAL OPTIONS OPEN TO THEM. IF THEY ARE NOT IN THE HANDS OF A TEAM THAT WILL DO ALL THAT IT CAN TO BRING THE PERTINENT AGENCIES INTO CONTACT WITH THE FAMILY FOR THEIR ULTIMATE BENEFIT, THEY WILL HAVE TO FORAGE FOR THEMSELVES. THESE PARENTS SEEK ON THEIR OWN WHAT SOCIETY HAS TO OFFER AND ON OCCASION WHEN THEY FIND SOCIETY'S EFFORT TO BE LESS THAN ADEQUATE, THEY EITHER RESTRUCTURE THE LIVES OF THEIR FAMILY TO FIT THE INADEQUATE PROVISIONS OR THEY ATTEMPT TO BE INNOVATIVE ENOUGH TO START IN MOTION SUPPORTIVE SERVICES THAT WILL BENEFIT NOT ONLY THEIR CHILD BUT OTHERS WITH SIMILAR PROBLEMS.

THIS REACTION OF FAMILIES HAS BEEN CLEARLY DOCUMENTED BY ROSALIND BENJAMIN DARLING IN A STUDY SHE DID ON TWENTY-FIVE (25) INTACT FAMILIES WHO WERE RAISING A CHILD WITH SPINA BIFIDA. IT IS APPROPRIATE THAT THE TITLE OF HER EXCELLENT BOOK IS <u>FAMILIES AGAINST SOCIETY</u>.

I HAD WRITTEN TO DR. DARLING MANY YEARS AGO AFTER SHE HAD PUBLISHED A JOURNAL ARTICLE ON SOCIAL ASPECTS OF THE MANAGEMENT OF SPINA BIFIDA AND TOLD HER THAT SHE WOULD NEVER COME TO AN UNDERSTANDING OF THESE PROBLEMS UNLESS SHE DID AN IN-DEPTH STUDY OF THE FAMILIES WHO HAD MANAGED TO COPE WITH

THE SITUATION. THIS SHE DID AND I THINK HER CONTRIBUTION HAS BEEN REMARKABLE. IN ONLY WISH IT WERE MORE WIDELY UNDERSTOOD.

SEVERAL YEARS AGO I DID TWO STUDIES OF SIMILAR NATURE, EACH ON TWENTY-FIVE (25) FAMILIES. THE FIRST WERE THE FAMILIES WHO HAD RAISED A CHILD WHOM I HAD PERSONALLY OPERATED UPON FOR IMPERFORATE ANUS MORE THAN FIFTEEN (15) YEARS BEFORE. IMPERFORATE ANUS IS A VERY FAR REACHING ANATOMIC AND SOCIAL ANOMALY. FAMILIES WHO MUST LIVE WITH A CHILD WHO IS BEING REHABILITATED INTO SOCIETY WHILE HE LEARNS TO BE CONTINENT HAVE GRAVE PROBLEMS THAT AFFECT MOTHER, FATHER, PATIENT, SIBLINGS AND CONTINGUOUS SOCIETY. THE SECOND GROUP OF PATIENTS THAT I STUDIED HAD ANOTHER LETHAL CONGENITAL ANOMALY,--ESOPHAGEAL ATRESIA. THESE WERE ALSO PATIENTS WHOM I HAD OPERATED UPON PERSONALLY AND THEY WERE ALL OPERATIONS THAT HAD TAKEN PLACE MORE THAN FIFTEEN (15) YEARS BEFORE.

ALTHOUGH MOTHERS VERSUS FATHERS HAD DIFFERENT PERCEPTIONS OF THE SITUATION, AND ALTHOUGH AN OCCASIONAL SIBLING BORE EARLY RESENTMENT TO THE PRESENCE OF A HANDICAPPED CHILD, AND IN SPITE OF THE FACT THAT SEVERAL OF THE FAMILIES WERE NEUTRAL AS TO WHAT THE EXPERIENCE HAD DONE FOR THEM, ON BALANCE A GREAT MAJORITY OF THE FAMILIES VIEWED THE EXPERIENCE OF RAISING THE HANDICAPPED CHILD AS BEING A

VERY POSITIVE ONE IN THE DEVELOPMENT OF THE FAMILY. THE DIVORCE RATE AMONG THE PARENTS OF THESE FIFTY (50) HANDICAPPED CHILDREN WAS LOWER THAN THE NATIONAL AVERAGE.

SEVERAL YEARS AGO I HAD TO GIVE A LECTURE ON INFANTICIDE AT YORK UNIVERSITY IN TORONTO AND BEFORE I WENT, I WANTED TO BE ABLE TO QUOTE IN AN ACCURATE FASHION THE MOTHER OF ONE OF MY PATIENTS BORN WITH MULTIPLE CONGENITAL DEFECTS. I POSED THE FOLLOWING QUESTION TO HER TELLING HER THAT I WAS GOING TO QUOTE HER IF SHE GAVE ME PERMISSION. IT WAS, "WHAT IS THE WORST THING THAT EVER HAPPENED TO YOU IN YOUR LIFE?" SHE REPLIED, "HAVING OUR SON BORN WITH ALL THOSE DEFECTS THAT REQUIRED THIRTY-SEVEN (37) OPERATIONS TO CORRECT." I REPLIED THAT I KNEW HER ANSWER WOULD BE THAT BECAUSE I HAD DONE TWENTY-TWO (22) OF THE OPERATIONS MYSELF AND HAD BEEN INVOLVED IN SOME WAY WITH ALL THE OTHERS. I THEN ASKED HER "WHAT WAS THE BEST THING THAT EVER HAPPENED IN YOUR LIFE?" SHE REPLIED: "HAVING OUR SON BORN WITH ALL THOSE DEFECTS THAT REQUIRED THIRTY-SEVEN (37) OPERATIONS TO CORRECT."

I KNOW EXACTLY WHAT THAT WOMEN MEANT. I HAVE FOLLOWED THIS WHOLE FAMILY IN ITS DEVELOPMENT. I KNOW WHERE THEY LIVE. I KNOW THE IMPACT THEY HAVE HAD UPON THE SOCIETY THAT IS AROUND THEM, AND I KNOW THAT THIS FAMILY BELIEVES THAT THE PARENTS ARE BETTER PEOPLE AND THAT THE THREE SIBLINGS

HAVE GROWN TO BE OUTSTANDING YOUNG MEN AND WOMEN BECAUSE OF THE LOVE AND THE UNDERSTANDING AND THE SACRIFICE THAT THEY EXPERIENCED IN ORDER TO RAISE MY PATIENT. I CAN TELL YOU WITHOUT QUESTION THAT THE RECOLLECTION OF THIS FAMILY IS ONE OF THE WARMEST REWARDS THAT I HAVE HAD IN THE PRACTICE OF PEDIATRIC SURGERY.

WHAT ARE THE POSITIONS OF THE PHYSICIANS? I THINK DARLING HAS PUT HER FINGER ON IT AS SHE SUMMARIZED THE IN-DEPTH INTERVIEWS SHE HAD WITH FIFTEEN (15) PEDIATRICIANS WHO WERE CARING FOR SPINA BIFIDA PATIENTS BEING RAISED IN INTACT FAMILIES. HERE IS HOW SHE SAID IT: "SOME DOCTORS WERE QUITE SYMPATHETIC TOWARD PARENTS OF HANDICAPPED CHILDREN. OTHERS WERE NOT. A FEW WERE DECIDEDLY HOSTILE TOWARD PARENTS WHO KEPT SUCH CHILDREN AT HOME. THESE DOCTORS' VIEWS ARE UNDERSTANDABLE WITHIN THE CONTEXT OF THEIR SOCIALIZATION IN THE STIGMATIZING SOCIETY AND THEIR TRAINING IN MEDICAL SCHOOL, WHERE SUCCESS IS TYPICALLY EQUATED WITH CURING AND NORMALCY OF FUNCTION AND PROBLEMS ARE TREATED ON AN INDIVIDUALISTIC RATHER THAN ON A SOCIETAL BASIS."

TO THAT I WOULD ADD THAT THE BASIC TENET UPON WHICH OUR INADEQUATE APPROACH TO THE TREATMENT OF THE HANDICAPPED CHILD AND HIS FAMILY RESTS IS THE ETHIC OF THE QUALITY OF LIFE AS BEING THE CRITERION UPON WHICH OUR DECISION TO TREAT OR NOT TO TREAT IS BASED.

IN LINE WITH WHAT I SAID PREVIOUSLY ABOUT FAMILIES AGAINST SOCIETY, I WOULD LIKE TO INVESTIGATE THE POSSIBILITY OF MAKING AVAILABLE TO PHYSICIANS AND PARENTS FOR EVERY CONGENITAL LESION AND SYNDROME A COMPREHENSIVE COMPUTERIZED SERVICE THAT COULD INFORM THEM OF THE MOST COMPETENT DIAGNOSTIC SERVICE CLOSEST TO THEIR HOME, THE CLOSEST COMPETENT THERAPEUTIC SERVICE, A LIST OF ALL OF THE AVAILABLE GOVERNMENTAL AND PRIVATE AGENCIES THAT COULD BE OF HELP TO THE PARENTS AND THE CHILDREN, AND FINALLY A READOUT OF PARENTS WITH SIMILAR SITUATIONS WHO HAVE MANAGED THE PROBLEM IN THE PAST SUCCESSFULLY. IF WE COULD MAKE THIS SERVICE AVAILABLE TO PARENTS AND PHYSICIANS ALIKE, I THINK WE WOULD REMOVE THE TERRIBLE FEAR THAT EXISTS THAT THE ODDS ARE TOO GREAT AGAINST THE HANDICAPPED CHILD AND HIS FAMILY TO MAKE ANY EFFORT WORTHWHILE AND TO SLAY FOREVER THE MYTH THAT ONLY PERFECT QUALITY OF LIFE IS LIFE WORTH LIVING.

IF THERE IS ANYTHING THAT ANNOYS ME MORE THAN DISCUSSIONS OF THE QUALITY OF LIFE AS THE CRITERION FOR SURVIVAL, IT IS COST EFFECTIVENESS,--BECAUSE I HAVE NEVER BEEN ABLE TO BRING MYSELF TO PUT A PRICE TAG ON A HUMAN LIFE. BUT I WOULD SUBMIT TO YOU THAT WE ARE CONSTANTLY BOMBARDED BY PROPAGANDA NOT ONLY IN THE LAY PRESS, BUT IN MEDICAL JOURNALS AS WELL CONCERNING THE COST OF THE HANDICAPPED TO SOCIETY AND THE COST OF THE RETARDED AND OTHERWISE MENTALLY DISADVANTAGED TO SOCIETY. THE COST FOR ALL OF THE PHYSICALLY HANDICAPPED INDIVIDUALS,

AND FOR ALL THE MENTALLY HANDICAPPED INDIVIDUALS ON OUR SOCIETY TODAY AND IN THE FUTURE IS BUT A DROP IN THE BUCKET COMPARED TO THE COST TO OUR SOCIETY FOR THE MORALLY HANDICAPPED.

I NEVER READ ANYTHING IN THE NEWSPAPERS ABOUT HOW THE PHYSICALLY HANDICAPPED HAVE PERPETRATED TREMENDOUS CRIMES AGAINST SOCIETY. THE SAME COULD BE SAID ABOUT THE MENTALLY HANDICAPPED. BUT THE HEADLINES IN OUR NEWSPAPERS AND THE COMMENTARIES IN OUR NEWS MAGAZINES CONSTANTLY BRING TO MIND THE FACT THAT WE ARE BURDENED ALMOST BEYOND OUR ABILITY TO STAND IT WITH THE COST OF THE MORALLY HANDICAPPED. THESE PEOPLE ARE NEVER CALLED THE MORALLY HANDICAPPED. THESE ARE THE PEOPLE WHO PERPETRATE OUR CRIMES AND KILL OUR CITIZENS. THESE ARE THE PEOPLE FOR WHOM WE ARE ASKED TO PROVIDE EVERY CONCEIVABLE REHABILITATION PROGRAM. WE ARE ASKED TO SEEK THAT THEY HAVE EASY SENTENCES WHEN CONVICTED. WE ARE INFORMED ABOUT THE ADVANTAGES OF PLEA BARGAINING. WHY THEN DO WE DEMAND PERFECTION FOR THOSE WHO HAVE PHYSICAL HANDICAPS AND THOSE WHO HAVE MENTAL HANDICAPS WHEN WE DO NOT EVEN ASK FOR NORMAL BEHAVIOR FROM THOSE WHO ARE MORALLY HANDICAPPED?

I WOULD ALSO LIKE TO ASK FOR WHOM IS THE HANDICAPPED CHILD SACRIFICED? FROM ALL THE ALTRUISTIC TALK, YOU MIGHT SUSPECT IT IS FOR THE CHILD HIMSELF. CLOSER INSPECTION REVEALS THAT IS TRULY NOT THE CASE. THEN YOU FALL BACK ON THE FACT THAT THE SOCIAL PLANNERS ARE CONCERNED ABOUT WHAT THE PARENTS HAVE TO COPE WITH IN DAYS AHEAD. BUT THAT IS REALLY NOT THE REASON FOR DISPOSING OF THE BLIGHTED CHILD. AS I HAVE WATCHED THIS OVER THE YEARS, I AM CONVINCED THAT THE PERSON WHO SAYS, "DON'T TREAT HIM," IS SAYING: "IF I WERE THE FATHER OR THE MOTHER OF THAT CHILD, I COULDN'T HACK IT AND I WOULD WISH SOMEBODY WOULD DISPOSE OF THE CHILD FOR ME." BUT THAT IS BECAUSE THAT INDIVIDUAL DOES NOT UNDERSTAND THE INATE LOVE OF PARENTS FOR A CHILD EVEN THOUGH HANDICAPPED NOR DO THEY UNDERSTAND HOW IN PROVIDING THE SPECIAL CARE THAT SUCH A YOUNGSTER NEEDS BUILDS A FAR GREATER LOVE THAN EXISTS BETWEEN NORMAL YOUNGSTERS AND THEIR PARENTS.

IN CLOSING, I TRUST YOU WILL FORGIVE ME IF I STEP INTO A FIELD THAT IS NOT MY OWN; NAMELY, THEOLOGY. I GUESS ONE OF THE MOST COMMONLY ASKED QUESTIONS OF SOMEONE WHO DEALS WITH THE HANDICAPPED IS: "WHY DID GOD DO THIS?" I FIND MYSELF FREQUENTLY SAYING THAT NO EVIL CAN COME FROM THE HAND OF GOD YET I BELIEVE SO TOTALLY AND THOROUGHLY IN HIS SOVEREIGNTY THAT I KNOW THE PROBLEM AT HAND IS NO ACCIDENT.

I MUST ACKNOWLEDGE THAT I TAKE A GREAT DEAL OF COMFORT FROM A CONVERSATION BETWEEN GOD AND MOSES AT THE BURNING BUSH. YOU WILL RECALL THAT GOD INSTRUCTED MOSES TO GO INTO EGYPT AND CONFRONT PHAROAH. AS WE ALL KNOW, MOSES HAD HIS REASONS WHY HE WAS NOT THE ONE TO CARRY OUT THIS TASK. HE SAID AMONG OTHER THINGS THAT HE WAS NOT ELOQUENT AND IN RESPONSE TO THAT, GOD SAID TO MOSES: "WHO MADE MAN'S MOUTH? WHO MADE THE DEAF OR THE DUMB OR THE SEEING OR THE BLIND? HAVE NOT I?" SAITH THE LORD.

SO I HAVE COME TO TAKE GREAT COMFORT IN THIS VERSE BECAUSE IT SAYS TO ME THAT AS HARD A DOCTRINE AS IT MIGHT BE AND AS MUCH AS I PERSONALLY MIGHT NOT LIKE IT, GOD ACKNOWLEDGES THAT THE IMPERFECT AS WELL AS THE PERFECT ARE EQUALLY HIS CHILDREN. I ALSO BELIEVE THAT HE COULD HAVE ADDED TO MOSES, "WHO MADE THE CHILD WITH IMPERFORATE ANUS, AN ESOPHAGEAL ATRESIA, AND MONGOLISM? HAVE NOT I?" BUT MOSES WOULD NOT HAVE UNDERSTOOD HIM. I THINK YOU AND I CAN UNDERSTAND HIM BY IMPLICATION.

THE SECOND THING THAT I HAVE TO ACKNOWLEDGE IS THAT WHAT THE WORLD LOOKS AT AS EVIL, GOD MAY NOT NECESSARILY CONSIDER IN THE SAME REALM. THE PORTUGUESE HAVE A SAYING; "GOD WRITES STRAIGHT WITH CROOKED LINES." TAKE THE MOTHER I USED AS AN EXAMPLE A SHORT WHILE AGO. I AM SURE THAT THE WORLD WOULD CONSIDER ANYTHING THAT PRODUCED A CHILD WHO REQUIRED THIRTY-SEVEN (37) OPERATIONS TO BECOME FUNCTIONAL WAS EVIL.

YET THE FAMILY IN THAT PARTICULAR INSTANCE BROUGHT FORTH A TREMENDOUS GOOD FROM THAT EVENT. AND I BELIEVE THAT THAT WAS BECAUSE OF THEIR THEOLOGICAL INSIGHT. AS I LOOK AT THE EFFECT OF THAT CHILD UPON HIS FAMILY AND UPON THE COMMUNITY, I THINK I SEE IT WITH GOD'S EYES. IT WAS MEANT AS THE OPPORTUNITY FOR GOOD WHICH FAR SURPASSED THE PHYSICAL EVIL OF THE CHILD'S HANDICAPS. AGAIN IF YOU LIKE A BIBLE VERSE THAT GOES ALONG WITH IT, THERE IS THAT WONDERFUL ONE IN THE 8TH CHAPTER OF ROMANS: "FOR WE KNOW THAT ALL THINGS WORK TOGETHER FOR GOOD TO THOSE WHO LOVE GOD,--TO THOSE WHO ARE THE CALLED ACCORDING TO HIS PURPOSE."

WHEN OUR OWN SON WAS KILLED AND MY WIFE AND I WROTE ABOUT IT IN A BOOK ENTITLED SOMETIMES MOUNTAINS MOVE, WE REFERRED TO THE TAPESTRY THAT GOD WEAVES AROUND THE LIVES OF HIS CHILDREN AND POINTED OUT THE FACT THAT SOME BONE CRUSHING GRIEF, SOME EARTH SHATTERING EVENT LIKE THE DEATH OF ONE'S CHILD IS BUT ONE STITCH IN THAT FABRIC. THE ONE STITCH MEANS NOTHING OF ITSELF, BUT AS YOU STAND BACK AND VIEW THE FABRIC, YOU CAN SEE HOW IT FITS INTO THE ENTIRE TAPESTRY.

I HAVE READ THE MANUSCRIPT OF A BOOK SOON TO BE PUBLISHED BY BONNIE JEAN WHEELER CALLED OF BRACES AND BLESSINGS. IN THE LAST CHAPTER SHE ALSO ALLUDES TO THE FABRIC THAT IS SEWN BY THE MASTER DESIGNER. PERHAPS IT IS BECAUSE OF THAT OR PERHAPS IT IS BECAUSE THE WORDS SAY SO MUCH THEMSELVES THAT I WOULD LIKE TO READ THE CLOSING LINES

OF A POEM THAT THIS GOOD WOMAN WROTE AS SHE REFLECTED UPON THE SEVEN CHILDREN UNDER HER CARE, SOME NATURAL-BORN, SOME ADOPTED, SOME WHITE, SOME OF OTHER COLORS, BUT ALL SEVEN HANDICAPPED:

"RED & YELLOW, BLACK & WHITE,
THEY'RE AT WHEELER'S HOUSE TONIGHT AND WOVEN
US INTO A FAMILY.
STITCH AFTER STITCH
WE'VE GONE THROUGH TESTINGS,
SEEN YOUR LOVE.
BEEN DOWN TO THE PITS AND
TOUCHED THE STARS.

STITCH AFTER STITCH
YOU'VE PATIENTLY AND LOVINGLY
TURNED OUR SORROWS INTO JOYS,
OUR TRAGEDY INTO TRIUMPH,
OUR PAIN INTO VICTORY
OUR BRACES INTO BLESSINGS."