

ORIGINAL  
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ADDRESS

BY  
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PRESENTED AT THE SURGEON GENERAL'S CONFERENCE ON  
COORDINATED CARE FOR THE CHRONICALLY ILL CHILD  
HOUSTON, TEXAS  
JUNE 14, 1987

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

I'M VERY PLEASED TO BE HERE THIS MORNING TO OPEN THIS WORKSHOP. I CONSIDER THIS MEETING TO BE A MEMORABLE WAY-STATION ON OUR LONG BUT SATISFYING JOURNEY TOGETHER...A JOURNEY THAT, SO FAR, HAS LASTED FOR FOUR CROWDED BUT FULFILLING YEARS...A JOURNEY THAT HAS, AS ITS GOAL, THE PROVISION OF BETTER CARE FOR CHRONICALLY ILL CHILDREN AND THEIR FAMILIES.

BACK IN DECEMBER OF 1982, I SAID THAT, IN MY OPINION, "THE WAY WE DEAL WITH PROBLEMS LIKE THIS" -- PROBLEMS INVOLVING HANDICAPPED CHILDREN AND THEIR FAMILIES -- "REVEALS JUST WHAT KIND OF SOCIETY WE ARE."

NOW, FOUR YEARS LATER, I CAN TELL THAT, AGAIN, IN MY OPINION,  
WE'RE A VERY GOOD SOCIETY INDEED. PERFECT? NO, NOT PERFECT.

BUT, AS A SOCIETY, I THINK THIS COUNTRY SHINES...

IN THE WAY IT INCLINES TOWARD MAKING COMPASSION MORE THAN A  
GESTURE AND MAKING DECISIONS TEMPERED WITH KINDNESS AND  
CONSIDERATION...

THE WAY IT PREFERS TO CARRY OUT A PROTOCOL THAT IS LIFE-  
FULFILLING, NOT LIFE-DENYING...

AND THE WAY IT TRIES, ABOVE ALL, TO BE FAIR AND JUST TO ALL ITS  
CITIZENS, EVEN THE VERY SMALLEST AND THE VERY NEWEST OF THEM.

YOU'VE DONE GOOD WORK PARTLY BECAUSE OF WHO YOU ARE...BUT ALSO  
PARTLY BECAUSE OF WHERE YOU ARE.

ALL OF YOU HAVE WORKED VERY HARD IN THIS PROGRAM...SPENT MONEY AND VALUABLE TIME...EXPENDED MUCH THOUGHT AND ENERGY...AND GENERATED NEW HOPE AT EVERY LEVEL OF YOUR INVOLVEMENT.

YOU'VE DONE IT AS PHYSICIANS AND AS NURSES...AS SOCIAL WORKERS AND AS PLANNERS...AS AUDITORS...AND, YES, AS CHILDREN AND AS PARENTS.

BUT YOU'VE ALSO DONE IT AS AMERICANS.

I'M MAKING THIS POINT BECAUSE, THUS FAR, THE WORK YOU'VE DONE HAS BEEN ACCOMPLISHED WITHIN A KNOWN AND ACCEPTED FRAMEWORK OF TRADITION AND LAW...A FRAMEWORK THAT IS VERY SPECIAL TO OUR SOCIETY AND OF WHICH WE ARE ITS CURRENT STEWARDS.

THAT TRADITION ASSERTS THAT EVERYBODY'S LIFE IS PRECIOUS...AND THE LAW SAYS THAT WE CAN MAKE NO DISTINCTIONS AS TO CLASS OR RACE OR CONDITION OR ABILITY OR DISABILITY.

THE TRADITION DEMANDS THAT SOCIETY RESPOND TO EVERY SERIOUS HUMAN NEED...AND THE LAW SAYS THAT WE MUST RESPOND, REGARDLESS OF GEOGRAPHY OR THE SEVERITY OF THE NEED.

AND TRADITION SAYS THAT WE SHOULD ACT WISELY OR, AT THE VERY LEAST, "DO NO HARM"...AND THE LAW SAYS WE SHOULD ACT IN A WAY CONSISTENT WITH THE NEEDS OF THE FAMILY AND OF THE COMMUNITY.

AND THAT'S HOW THIS PROGRAM HAS PROGRESSED OVER THE PAST FOUR YEARS.

YOU WILL RECALL THAT I MADE SOME REQUESTS OF THOSE PARTICIPANTS IN THE FIRST WORKSHOP BACK IN 1982.

I ASKED THEM TO COME UP WITH SOME GUIDANCE AS TO THE DIRECTION IN WHICH THIS SOCIETY SHOULD GO, IN ITS QUEST FOR IMPROVING THE CONDITION OF HANDI- CAPPED CHILDREN AND THEIR FAMILIES.

WHAT QUESTIONS NEED TO BE ASKED?

AND HOW SHOULD WE GO ABOUT GETTING THE ANSWERS?

WE BEGAN WITH A FOCUS ON THE VENTILATOR-DEPENDENT CHILD BECAUSE SOME PROBLEMS HAD BEEN RAISED AND WE NEEDED IMMEDIATE ANSWERS.

BUT WE ALSO FELT THAT IF WE COULD DO SOMETHING NEW AND CREATIVE FOR CHILDREN WITH THIS TYPE OF DISABILITY, PROBABLY THE MOST COMPLICATED AND EXPENSIVE OF ALL -- AND FOR THEIR FAMILIES AS WELL -- THEN WE JUST MIGHT GAIN ENOUGH INSIGHT TO DO SOMETHING NEW AND CREATIVE FOR CHILDREN WITH OTHER TYPES OF CHRONIC ILLNESSS AND DISABILITIES, ALSO.

YOU WILL RECALL THAT THE PARTICIPANTS AT THE 1982 WORKSHOP RECOMMENDED...

THAT WE BE MORE PRECISE IN THE WAY WE DEFINE THE PROBLEM...

THAT WE DEVELOP MODEL STANDARDS AND SYSTEMS OF REGIONALIZED CARE THAT PROMOTE, NOT IMPEDE, THE PROCESSES OF CARE...

THAT WE CONFRONT THE ISSUE OF COSTS -- AND HOW TO PAY THEM...

THAT WE LOOK AT TRAINING ACROSS ALL DISCIPLINES...

AND THAT WE ASSURE AN ON-GOING AND FRUITFUL RESEARCH EFFORT IN THIS AREA.

FOLLOWING THAT WORKSHOP IN DECEMBER OF 1982, 5 OR 6 REGIONAL WORKSHOPS WERE HELD AROUND THE COUNTRY AND OUR DIVISION OF MATERNAL AND CHILD HEALTH FUNDED ABOUT 25 PROJECTS AND STUDIES. BUT THAT WAS JUST THE BEGINNING.



THE FACT OF THE MATTER IS THAT MOST OF THE TALENT AND ENERGY... AND MONEY AND EFFORT... PUT FORTH IN THE PAST FOUR YEARS HAVE COME FROM STATE AND COUNTY GOVERNMENTS...FROM MUNICIPALITIES...FROM FOUNDATIONS AND VOLUNTARY ORGANIZATIONS...FROM PARENT GROUPS...FROM PROFESSIONAL ASSOCIATIONS...AND FROM BRAND-NEW ORGANIZATIONS CREATED FOR THE SPECIAL PURPOSE OF RESPONDING TO THE SPECIAL HEALTH CARE NEEDS OF DISABLED AND CHRONICALLY ILL CHILDREN AND THEIR FAMILIES.

THE FEDERAL GOVERNMENT HAS HELPED GET SOME THINGS STARTED AND HAS MADE THE ISSUE CLEARLY VISIBLE TO ANYONE OR ANY GROUP EVEN MILDLY INTERESTED IN THIS AREA.

BUT OTHER LEVELS OF GOVERNMENT AND THE PRIVATE SECTOR HAVE DEMONSTRATED EXTRAORDINARY LEADERSHIP THROUGHOUT THIS PROGRAM, AND I WOULD GUESS THAT THAT'S A FACTOR THAT OUGHT TO GUARANTEE LONGEVITY FOR MOST OF THE NEW PROJECTS UNDER WAY.

ALL THIS INFORMATION IS COLLECTED TOGETHER IN THE SURGEON GENERAL'S REPORT TITLED "CHILDREN WITH SPECIAL HEALTH CARE NEEDS," WHICH EACH OF YOU SHOULD HAVE RECEIVED AT REGISTRATION.

THE CONTENT OF THAT REPORT IS WHAT THIS MEETING IS ALL ABOUT.

AS YOU SCAN THIS REPORT -- AND AS YOU HEAR FROM THE MANY PEOPLE WHO ARE MAKING PRESENTATIONS AT THIS MEETING -- I WANT YOU TO THINK ABOUT THE NEXT STAGE IN THIS JOURNEY.

IT'S A STAGE THAT WAS NOT CLEARLY ENVISIONED, WHEN THIS PROGRAM FIRST TOOK SHAPE IN 1982. WE MAY HAVE USED THE WORDS AND PHRASES... BUT I'M NOT SURE WE EVEN SUSPECTED, AT THAT TIME, WHAT WE NOW KNOW TO BE TRUE. FOR EXAMPLE...

- \* WE SPOKE OFTEN OF THE NEED FOR COORDINATION. TODAY WE KNOW FOR A CERTAINTY THAT IT IS NOT ONLY ADVISABLE, IT'S ENTIRELY POSSIBLE TO COORDINATE THE HEALTH AND SOCIAL SERVICES NEEDED BY CHRONICALLY ILL AND DISABLED CHILDREN AND THEIR FAMILIES.

THE COORDINATION OF CARE SHOULD BE DONE...IT CAN BE DONE...AND WE NOW KNOW EXACTLY WHERE AND HOW IT IS BEING DONE. WE HAVE ONLY TO LOOK AT THE GEORGETOWN PROJECT IN NETWORKING..."PROJECT SERVE" IN MASSACHUSETTS...AND THE "PATHFINDER" PROGRAM IN MINNEAPOLIS, FOR A START.

AND OF COURSE THIS AFTERNOON YOU WILL HEAR OUR HOST, DR. EARL BREWER, AND HIS COLLEAGUES TELL US HOW TEXAS IS "MAKING IT HAPPEN."

- \* WE ALSO SPOKE WISTFULLY OF THE NEED FOR COMMUNITY-BASED HEALTH CARE. BUT WE DON'T HAVE TO BE SO WISTFUL ANY MORE. WE'VE SINCE DISCOVERED THAT COMMUNITIES OF EVERY SIZE AND EVERY CAPABILITY CARE ENOUGH ABOUT CHILDREN TO PULL TOGETHER ALL THE NECESSARY RESOURCES AND SERVICES TO MAKE LIFE A LITTLE BETTER...A LITTLE RICHER...AND A LITTLE LONGER FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

YOU CAN LOOK AT THE "COORDINATE FOR KIDS" PROJECT IN OKLAHOMA  
...THE IOWA PROGRAM OF REGIONAL CENTERS...THE HAWAII PROJECTS  
...THE MICHIGAN PROGRAM OF LOCALLY BASED SERVICES...AND YOU WILL  
SEE COMMUNITIES THAT ARE RESPONDING -- AND ARE RESPONSIBLE.

AND I KNOW THAT THESE COMMUNITY-BASED PROJECTS CAN BE REPLICATED  
RIGHT ACROSS AMERICA.

- \* AND FINALLY, WE LOOKED TO A FUTURE IN WHICH THE FAMILY WAS THE  
CENTER OF THE HEALTH CARE DELIVERY SYSTEM. WELL, I'D SAY THE  
FUTURE IS ALMOST HERE. IT'S CLEAR FROM THE REPORT THAT WE'VE  
LEARNED THAT CHILDREN DO BEST WHEN THEIR PARENTS ARE INTIMATELY  
AND ROUTINELY INVOLVED IN THE DECISION-MAKING AFFECTING THE  
DELIVERY OF SPECIAL HEALTH CARE. WE'VE CONVERTED THE PHRASE  
"FAMILY-CENTERED" FROM A CONCEPT TO A REALITY.

THE FIELD OF SPECIAL HEALTH CARE DOES NOT EXIST BECAUSE THERE ARE PROFESSIONAL PEOPLE AROUND WHO HAVE BEEN TRAINED TO DELIVER SUCH CARE. IT EXISTS BECAUSE THERE ARE CHILDREN AND FAMILIES WHO NEED SUCH CARE. THEY -- NOT WE -- OUGHT TO BE AT THE CENTER OF THE PLANNING AND IMPLEMENTATION OF HEALTH CARE DELIVERY.

IS THAT STILL AN IDEAL, OR HAS IT BECOME A REALITY? IT SEEMS TO ME THAT IT IS REAL ENOUGH IN THE NEW MEXICO PROJECT, THE ONE THAT GIVES SPECIAL ATTENTION TO NATIVE AMERICAN CHILDREN AND THEIR FAMILIES ...IT'S ALSO PART OF THE ACADEMY'S "PROJECT BRIDGE"... IT'S AT THE HEART OF THE C.A.P.P. PROJECT IN BOSTON...AND SO ON.

AND WE'VE ALSO LEARNED THAT GOOD HEALTH CARE IS NOT NECESSARILY EXPENSIVE HEALTH CARE. IN FACT, THIS REPORT INDICATES HOW COST-EFFECTIVE A FAMILY-CENTERED, COMMUNITY-BASED PROGRAM OF COORDINATED CARE CAN REALLY BE.

IF THIS IS A CULMINATION...THEN WHY NOT JUST SEND EVERYBODY A COPY OF THE REPORT WITH A LITTLE "THANK-YOU" NOTE ATTACHED? WHY HAVE ANOTHER WORKSHOP?

GOOD QUESTION. BUT THE ANSWER IS BETTER.

THIS IS TO BE THE WORKSHOP THAT WILL TURN AN ARRAY OF EXCELLENT EXAMPLES...INTO A NATIONAL GRASSROOTS PROGRAM.

OUR CHARGE THIS WEEK IS TO REVIEW THE QUESTIONS THAT WE'VE BEEN ASKING...LOOK AGAIN AT THE ANSWERS THAT HAVE BEEN GENERATED...FIT THE PIECES TOGETHER...AND SEE IT ALL AS A SINGLE, MAJOR NATIONAL MOVEMENT ON BEHALF OF CHRONICALLY ILL CHILDREN AND THEIR FAMILIES.

FURTHER, WE MUST MAKE SURE THAT THE REST OF SOCIETY KNOWS THAT SUCH A MOVEMENT EXISTS AND THAT THERE'S STILL ROOM FOR MORE GOVERNMENT AGENCIES AND PRIVATE ORGANIZATIONS TO JOIN.

WITH THE REPORT IN YOUR HANDS TODAY, YOU CAN BEGIN TO SEE THE PATTERNS OF CARE THAT ARE EMERGING...YOU CAN BEGIN TO SENSE THE DIRECTION IN WHICH PROGRAMS AND RESEARCH AND TRAINING SEEM TO BE GOING...AND YOU CAN BEGIN TO FEEL THE HEIGHTENED PERSONAL AND PROFESSIONAL PRIDE THAT COMES WITH PROVIDING A QUALITY SERVICE FOR CHILDREN AND FAMILIES WITH VERY SPECIAL NEEDS.

THIS IS A TIME OF GREAT OPPORTUNITY. WE HAVE SOME MOMENTUM... LET'S NOT LOSE IT.

HENCE, I AM ASKING ALL FAMILIES TO BECOME MORE ACTIVE IN THE DEVELOPMENT OF PROGRAMS THAT SERVE THEIR CHILDREN...

AND I'M ASKING ALL STATE AGENCIES TO ESTABLISH WORKING RELATIONSHIPS WITH FAMILIES AND USE THESE PARTNERS TO FULL MUTUAL ADVANTAGE...

AND I'M ASKING ALL PRIVATE HEALTH CARE PROVIDERS TO OPEN UP THE SYSTEM OF HEALTH CARE AT ALL LEVELS AND HELP MAKE THEM FULLY ACCESSIBLE BY ALL FAMILIES AND CHILDREN IN NEED...

AND I'M ASKING ALL MEMBERS OF THE HEALTH CARE FINANCING SECTOR -- PUBLIC AND PRIVATE -- TO RE-EXAMINE THEIR POLICIES AND MAKE THE NECESSARY ADJUSTMENTS SO THAT ALL CHILDREN WITH SPECIAL HEALTH NEEDS WILL HAVE ACCESS TO QUALITY HEALTH CARE AND NONE WILL BE DENIED BECAUSE OF COSTS.

THOSE ARE THE QUESTIONS WITH WHICH I WANT TO OPEN THIS PARTICULAR SURGEON GENERAL'S WORKSHOP. WE'VE BEGUN TO SHAPE SOME ANSWERS WITH THE KINDS OF ACTIVITIES DESCRIBED IN THE REPORT.

BUT, AS GOOD AS THOSE ANSWERS ARE, THEY'RE STILL NOT COMPLETE ENOUGH FOR THE CHILDREN WE WISH TO SERVE.



I BELIEVE THE MOST COMPLETE ANSWERS WILL LIE IN THE HISTORY THAT,  
TOGETHER, WE YET INTEND TO MAKE. AND WITH THAT...LET US BEGIN.

THANK YOU.

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