

ORIGINAL

#4 / DOWN'S

ADDRESS

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PRESENTED TO THE NATIONAL DOWN SYNDROME CONGRESS

CINCINNATI, OHIO

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

I'M VERY PLEASED TO JOIN YOU AT THIS, YOUR 16<sup>TH</sup> ANNUAL CONVENTION.

THE LAST TIME I MET WITH YOU, WE WERE IN THE MIDST OF A PROFOUNDLY SIGNIFICANT NATIONAL DEBATE THAT HAD BEEN SET OFF BY THE TRAGIC CIRCUMSTANCES SURROUNDING THE BIRTH AND UNTIMELY DEATH, A WEEK LATER, OF "BABY DOE."

AT THAT TIME, WE -- YOU AND I TOGETHER -- TRIED TO SHARE WITH THE REST OF THE COUNTRY OUR DEEPEST FEELINGS ABOUT LIFE ... ITS SUPREME VALUE ... AND OUR TOTAL COMMITMENT TO CHILDREN ... AND THEIR SUPREME VALUE TO US, OUR FAMILIES AND COMMUNITIES, AND OUR NATION.

EVERY TIME I SAY SOMETHING LIKE THAT, I THINK TO MYSELF, "GOD BLESS MADELEINE WILL."

IT WAS NOT AN EASY TIME. BUT I THINK WE CAME THROUGH THAT IMMEDIATE PERIOD WITH DETERMINATION ... AND HONESTY ... AND COURAGE. AND I THINK THE REST OF THE COUNTRY LEARNED SOMETHING FROM US ... WHETHER THEY WANTED TO OR NOT.

I THINK THE REST OF THE COUNTRY LEARNED THAT IF YOU LOVE A CHILD ... EVERY CHILD ... IT WILL BE VERY GOOD FOR BOTH OF YOU.

I THINK THE COUNTRY ALSO LEARNED THAT THERE REALLY ARE SOME THINGS YOU CAN'T PUT A PRICE-TAG ON, AND YOU JUST CAN'T BUY OR SELL ... EVEN HERE IN THE UNITED STATES, THE CONSUMER'S PARADISE ON EARTH.

AND THAT AT THE TOP OF THE LIST ARE SUCH THINGS AS DECENCY AND COMPASSION ... MERCY AND HOPE ... AND THE LOVE OF A PARENT FOR A CHILD.

THOSE THINGS AREN'T FOR SALE. THEY'RE NOT EVEN SUBJECTS FOR NEGOTIATION.

I THINK WE TOOK THE COUNTRY BY THE LAPELS AND GAVE IT A GOOD SHAKE AND, IN SO DOING, MADE AMERICA TRY HARDER TO BE AS GOOD AS IT'S SUPPOSED TO BE -- AND AS GOOD AS IT CAN BE -- FOR ALL ITS CITIZENS, INCLUDING ITS TINIEST AND MOST DISADVANTAGED CITIZENS.

I THINK WE DID THAT, AT THE LOCAL, STATE, REGIONAL, AND NATIONAL LEVELS. AND WE'VE BEEN ABLE TO SAVE THOUSANDS AND THOUSANDS OF HUMAN LIVES EVER SINCE.

BUT I HAVE NOT COME HERE THIS MORNING TO CELEBRATE PAST ACCOMPLISHMENTS, AS APPEALING AS THAT IDEA MAY BE. WE STILL HAVE TOO MUCH TO DO ON BEHALF OF CHILDREN WITH DOWN SYNDROME TO WASTE TIME RESTING ON OUR LAURELS.

INSTEAD, I WANT TO LOOK AHEAD AND SEE WHAT KIND OF CHALLENGES LIE WAITING FOR US IN THE FUTURE. AND I SEE TWO OF THEM:

THE FIRST ONE IS THE THEME OF THIS YEAR'S CONVENTION AND IT'S A SERIOUS CHALLENGE INDEED ... THE CHALLENGE OF ACCESS TO CARE.

AND THE SECOND ONE -- AND IT IS RELATED TO THE FIRST -- IS THE CHALLENGE OF THE CONTINUITY OF CARE.

YOUR PROGRAM LISTS MANY EXPERTS MORE KNOWLEDGEABLE THAN I, IN REGARD TO ACCESS TO CARE, SO I WILL MAKE JUST A FEW COMMENTS RELATING TO MY PARTICULAR PERSPECTIVE AS YOUR SURGEON GENERAL.

MY CONCERN HAS HAD TO BE FOR ALL OF AMERICA'S CHILDREN WITH SPECIAL HEALTH NEEDS. I DO NOT SEE THEM AND THEIR PARENTS IN A CONTEST OR A COMPETITION FOR ATTENTION AND ASSISTANCE. I SEE THEM ALL AS EQUALLY IMPORTANT AND EQUALLY DESERVING OF THE BEST ATTENTION THAT OUR SOCIETY CAN GIVE.

TO THIS END, YOU WILL RECALL THAT, EARLY IN MY FIRST TERM AS SURGEON GENERAL, I CONVENED A "SURGEON GENERAL'S WORKSHOP ON CHILDREN WITH HANDICAPS AND THEIR FAMILIES." OUT OF THAT WORKSHOP CAME A SERIES OF ACTION STEPS DIRECTED PRIMARILY AT THE IMPROVEMENT OF LOCAL SYSTEMS OF CARE AND OF THE FINANCING OF SUCH CARE.

IN THE 5 YEARS SINCE THAT WORKSHOP WAS HELD, WE'VE HAD MANY LOCAL, STATE, AND REGIONAL MEETINGS ... MANY NEW PROGRAMS AT ALL LEVELS OF GOVERNMENT ... AND SUBSTANTIAL IMPROVEMENTS IN THE DELIVERY OF CARE IN A GREAT MANY AREAS.



JUST A LIST OF THE RESULTS OF THAT INITIAL WORKSHOP WOULD  
FILL A VERY LARGE AND THICK VOLUME INDEED.

BUT ALONG THE WAY, WE LEARNED THAT A PARTICULAR ELEMENT  
NEEDED SPECIAL EMPHASIS, AND THAT ELEMENT HAS COME TO BE KNOWN AS  
"FAMILY-CENTERED, COMMUNITY-BASED, COORDINATED HEALTH CARE."

IN A SENSE, WE "CODIFIED" THIS APPROACH IN A "SURGEON  
GENERAL'S WORKSHOP ON CHILDREN WITH SPECIAL HEALTH CARE NEEDS,"  
WHICH WE HELD IN HOUSTON, TEXAS, IN JUNE OF 1987.

THE APPROACH WAS ONE OF 7 "ACTION STEPS" THAT WERE PROPOSED BY THE BROAD CROSS-SECTION OF HEALTH PROFESSIONALS, FAMILY AND CHILD ADVOCATES, AND GOVERNMENT AND NON-GOVERNMENT EXPERTS WHO ATTENDED.

AND JUST THIS PAST SEPTEMBER, I CONVENED A THIRD MEETING ON THIS SUBJECT IN WASHINGTON. ONCE AGAIN WE BROUGHT TOGETHER A GREAT NUMBER OF INDIVIDUALS FROM ACROSS A BROAD SPECTRUM OF HEALTH AND SOCIAL SERVICES. ALL THE PARTICIPANTS HAVE SOMETHING TO CONTRIBUTE TO THE NEEDS OF CHILDREN WITH SPECIAL HEALTH PROBLEMS ... PROBLEMS WHICH REQUIRE MORE THAN ROUTINE CARE.

IN EACH OF THESE MEETINGS, GOING BACK NOW FOR MORE THAN 5 YEARS, THE ADVOCATES FOR DOWN SYNDROME CHILDREN AND THEIR FAMILIES HAVE BEEN PROMINENT AND EXTREMELY HELPFUL. AND EACH TIME, THEY HAVE MADE IMPORTANT CONTRIBUTIONS TO HELP OUR COUNTRY RESOLVE THOSE FEW REMAINING ISSUES THAT IMPEDE THE DELIVERY OF QUALITY HEALTH AND SOCIAL SERVICES TO CHILDREN WITH SPECIAL NEEDS AND TO THEIR FAMILIES AS WELL.

I BELIEVE THE ANSWER TO THE ISSUE OF ACCESS LIES WITHIN THIS CONCEPT OF FAMILY-CENTERED, COMMUNITY-BASED SYSTEMS OF HEALTH CARE. WE'VE GOT TO GET AWAY FROM DELIVERY SYSTEMS THAT ARE -- AND REMAIN -- INSTITUTION-BASED AND SELF-PERPETUATING, COME-WHAT-MAY.

TIMES CHANGE, THE NEEDS OF CHILDREN AND FAMILIES CHANGE, AND -- TO BE EFFECTIVE AND ALSO COST-EFFECTIVE -- THE PROVIDERS OF HEALTH AND SOCIAL SERVICES MUST BE ABLE TO CHANGE AS WELL.

AND THEY WILL ... ONCE THEY SHIFT THEIR EMPHASIS AND THEIR REASON-FOR-BEING AWAY FROM THEIR OWN AGENCY OR INSTITUTIONAL BASE AND TOWARD THE FAMILIES AND CHILDREN THEY SERVE.

WE'RE FIGHTING INERTIA HERE.

WE'RE FIGHTING THE TENDENCY TO DO THINGS ONE WAY BECAUSE THEY'VE ALWAYS BEEN DONE THAT WAY.

WE'RE FIGHTING VESTED PROFESSIONAL INTERESTS, COMMONLY KNOWN AS "TURF."

WE'RE FIGHTING THE KIND OF BUREAUCRATIC "DIVIDE-AND-CONQUER" STRATEGY THAT KEEPS FAMILIES DEPENDENT ON THE SYSTEM, WHETHER IT'S RESPONSIVE OR NOT, INSTEAD OF THE OTHER WAY AROUND ... THAT IS, INSTEAD OF MAKING SURE THAT THE SYSTEM IS DEPENDENT ON THE NEEDS AND WISHES AND APPROVAL OF SPECIAL CARE CHILDREN AND THEIR FAMILIES.

I KNOW THAT "FAMILY-CENTERED, COMMUNITY-BASED, COMPREHENSIVE HEALTH AND SOCIAL SERVICE" IS QUITE A MOUTHFUL AND, THEREFORE, IS PROBABLY HELD IN SUSPICION BY PLAIN-SPEAKING CITIZENS.

SO LET'S JUST CALL IT "PEOPLE-CENTERED CARE" AND LET IT GO AT THAT. BECAUSE BASICALLY THAT'S WHAT I'M TALKING ABOUT ... PEOPLE-CENTERED, RATHER THAN AGENCY-CENTERED OR HOSPITAL-CENTERED OR PROFESSION-CENTERED CARE.

I BELIEVE THAT KIND OF CHANGE, NOW GOING ON IN COMMUNITIES ACROSS THIS COUNTRY, WILL SIGNIFICANTLY EXPAND THE ACCESS TO CARE THAT WE ALL WANT FOR CHILDREN WITH DOWN SYNDROME AND WITH OTHER SPECIAL PHYSICAL AND MENTAL HEALTH CONDITIONS.

THAT'S THE FIRST CHALLENGE AND THAT'S MY PERCEPTION OF HOW IT IS BEING MET ... AND SHOULD CONTINUE TO BE MET ... UNTIL ACCESS TO CARE IS ASSURED FOR EVERY CHILD AND FAMILY WITH SPECIAL NEEDS.

AS TO THE SECOND CHALLENGE -- THE GUARANTEE OF CONTINUITY OF CARE FOR CHILDREN WITH SPECIAL HEALTH NEEDS -- IT REQUIRES SOME NEW THINKING ON EVERYONE'S PART.

THIS IS THE SITUATION TODAY:

A CHILD WITH DOWN SYNDROME IS IN THE CARE OF A PEDIATRICIAN  
FROM BIRTH ...

THE CHILD GROWS UP ... THROUGH ADOLESCENCE ... AND ON INTO  
THE LATE TEENS...

AT THAT POINT THE PEDIATRICIAN SUGGESTS TO THE FAMILY THAT  
THEIR CHILD'S HEALTH NEEDS WOULD RECEIVE A MORE  
APPROPRIATE RESPONSE FROM AN INTERNIST OR FAMILY  
PHYSICIAN ...

THEY ALL AGREE AND THE CHILD IS TAKEN TO AN INTERNIST ...  
WHO HAS NO CLEAR IDEA AS TO WHAT TO DO NEXT.



IF THERE IS ANY "POINT OF DISJUNCTION" IN THE HEALTH SYSTEM FOR CHILDREN WITH DOWN SYNDROME OR ANY OTHER DEVELOPMENTAL PROBLEM, THAT'S THE POINT RIGHT THERE, WHEN THE CHILD PASSES FROM THE CARE OF A PEDIATRICIAN AND INTO THE CARE OF ANOTHER SPECIALTY.

MOST PEDIATRICIANS DO NOT FEEL THE NEED TO PASS ALONG ANY MORE THAN VAGUE, GENERALIZED INFORMATION ABOUT THE CHILD AND HIS OR HER SPECIAL NEEDS, ASSUMING -- I WOULD GUESS -- THAT THE NEXT PHYSICIAN WILL KNOW WHAT THE PROBLEMS ARE ANYWAY.

BUT MOST NON-PEDIATRIC PHYSICIANS DO NOT KNOW THE PROBLEMS ASSOCIATED WITH DOWN SYNDROME ... MOST HAVE HAD NO TRAINING OR EXPERIENCE WITH THE SYNDROME ... AND FEW HAVE WORKED CLOSELY WITH FAMILIES OR WITH COMMUNITY ORGANIZATIONS SERVING CHILDREN OR ADULTS WITH DOWN SYNDROME.

WHICH MEANS THAT, EITHER BOTH PATIENT AND PHYSICIAN MUST GO THROUGH A LONG ORIENTATION PERIOD TOGETHER, OR -- WORSE YET -- BOTH PHYSICIAN AND PATIENT WILL SEE LESS OF EACH OTHER THAN THEY SHOULD.

I'VE GIVEN SOME THOUGHT TO THIS PROBLEM OF THE "DISJUNCTION OF CARE" THAT OCCURS AMONG PATIENTS WITH DOWN SYNDROME, AT LEAST ENOUGH THOUGH TO KNOW THAT THE PROBLEM IS EASIER TO DESCRIBE THAN IT IS TO SOLVE.

THEREFORE, I'VE SET THE WHEELS IN MOTION TO BRING A GROUP OF PEOPLE TOGETHER TO FOCUS ON THE PROBLEM AND COME UP WITH SOME GOOD SUGGESTIONS FOR CORRECTING IT.

FOR PLANNING PURPOSES WE'RE CALLING IT A "SURGEON GENERAL'S WORKSHOP ON THE TRANSITION OF HEALTH CARE FOR ADOLESCENTS WITH SPECIAL NEEDS."

THESE DAYS IN WASHINGTON, IF YOU USE THE WORD "TRANSITION" ALL BY ITSELF, EVERYBODY ASSUMES YOU WORK FOR PRESIDENT-ELECT GEORGE BUSH AND YOU WIND UP WITH A LOT OF RESUMES OF PEOPLE YOU DON'T KNOW AND CAN'T HELP.

SO WE HAVE TO QUALIFY THE TITLE OF THE CONFERENCE. MAYBE THINGS WILL BE A LITTLE SIMPLER BY THE TIME I CONVENE THE CONFERENCE SOMETIME IN MARCH OF '89.

SINCE THIS IS OUR FIRST CRACK AT THE PROBLEM, WE'RE GOING TO KEEP IT SMALL -- ABOUT 50 PEOPLE OR SO -- EACH ONE INVITED BECAUSE OF HIS OR HER SPECIAL KNOWLEDGE OF OR EXPERIENCE WITH THE ISSUE.

OR BECAUSE THAT PERSON ALREADY HAS AN APPROACH THAT SEEMS TO WORK.

WE'LL NEED TO BRING TOGETHER PEOPLE WHO ARE FAMILIAR WITH GRADUATE MEDICAL EDUCATION AND CONTINUING MEDICAL EDUCATION. FURTHERMORE, THOSE SAME PEOPLE MIGHT ALSO HAVE SOME IDEAS OF HOW OUR PARTICULAR PROBLEM OF "TRANSITION" MIGHT BE SPECIFICALLY ADDRESSED AT SOME POINT DURING A PHYSICIAN'S EDUCATION AND TRAINING.

THAT'S A TOUGH ONE, BECAUSE -- AS YOU CAN IMAGINE -- JUST ABOUT EVERY INTEREST GROUP IN THE COUNTRY WANTS PHYSICIANS TO KNOW ABOUT THEIR SPECIAL PROBLEM.

AND THE AVERAGE MEDICAL SCHOOL CURRICULUM IS ALREADY JAMMED WITH MORE MATERIAL THAN CAN BE COVERED EVEN IN A 30-HOUR DAY.

SO WE'LL NEED SOME EXPERTS FROM THAT FIELD.

AND WE'LL NEED PEOPLE WHO UNDERSTAND GROWTH AND HUMAN DEVELOPMENT, PARTICULARLY AMONG CHILDREN, ADOLESCENTS, AND ADULTS WITH SPECIAL HEALTH NEEDS.

HERE AGAIN, WE'RE STILL BUILDING OUR KNOWLEDGE BASE FOR HUMAN GROWTH AND DEVELOPMENT AS IT OCCURS AMONG AVERAGE MEN AND WOMEN. WE DON'T HAVE MUCH TO GO ON, AS FAR AS GROWTH AND DEVELOPMENT OF EXCEPTIONAL OR NON-AVERAGE PEOPLE ARE CONCERNED.

BUT THAT'S NOT REASON ENOUGH TO CANCEL THE CONFERENCE EITHER. SO WE'LL FIND SOME PEOPLE TO HELP US GET A HANDLE ON THAT AREA AS WELL.

AND WE'LL NEED SOME ADVICE AND COUNSEL IN REGARD TO CONFIDENTIALITY AND COUNSELING AND FAMILY SERVICES AND SO ON. I EXPECT THAT OUR MAXIMUM OF 50 PEOPLE WILL BE REACHED RATHER QUICKLY, ONCE WE BEGIN TO PUT OUR LIST TOGETHER.

EVEN SO, I'D APPRECIATE ANY SUGGESTIONS THAT ANY OF YOU MIGHT HAVE, AS TO EXPERTS WHO MIGHT MAKE A STRONG CONTRIBUTION TO SUCH A CONFERENCE EARLY NEXT YEAR.

NATURALLY WE WILL INCLUDE PEOPLE FAMILIAR WITH THE TRANSITION PROBLEMS OF YOUNG PEOPLE WITH DOWN SYNDROME. BUT, AS WITH THE OTHER WORKSHOPS I HAVE HELD, THIS ONE, TOO, WILL COVER THE TRANSITION PROBLEMS OF ALL YOUNG PEOPLE WITH SPECIAL HEALTH NEEDS OF MANY DIFFERENT KINDS ... PHYSICAL, MENTAL, EMOTIONAL, DEVELOPMENTAL, AND SO ON.

BUT IT WILL FOCUS ON HEALTH AND NOT ON EDUCATION OR VOCATIONAL REHABILITATION, AND SO ON.

AND WE WILL ALSO TRY TO HAVE A DIALOGUE WITH INSURANCE CARRIERS.



I LOOK FORWARD TO THAT MEETING, ALTHOUGH I KNOW IT MAY BE AMONG THE LAST ONES THAT I, AS YOUR SURGEON GENERAL, WILL CONVENE -- OR EVEN ATTEND -- ON THE SUBJECT OF HANDICAPPED OR DISABLED CHILDREN.

I'VE ALREADY BEGUN THE LAST YEAR OF MY SECOND TERM AND I'M TOLD THAT NO TIME GOES BY QUITE AS FAST AS THE LAST YEAR OF GOVERNMENT SERVICE. AND I'M BEGINNING TO BELIEVE IT.

SO MANY THINGS TO DO ... SO LITTLE TIME LEFT TO DO THEM IN.

BUT I MAY HAVE AN ADVANTAGE OVER MANY OTHERS WHO HAVE BEEN IN MY POSITION. I KNOW THAT YOU AND I HAVE BEEN STRONG AND ACTIVE PARTNERS ON BEHALF OF PEOPLE WITH DOWN SYNDROME. AND I KNOW THAT OUR COMMITMENT TO DO MORE -- REGARDLESS OF WHO IS IN OR OUT OF OFFICE -- IS AN UNSHAKABLE COMMITMENT.

AT THIS TIME NEXT YEAR, I MAY BE OUT OF UNIFORM, BUT I WON'T BE OUT OF TOUCH. I CAN PROMISE YOU THAT.

SO LET ME CLOSE MY REMARKS THIS MORNING WITH A VERY SINCERE "THANK YOU" FOR INVITING ME TO YOUR CONVENTION ONCE AGAIN ... AND AN ADDITIONAL "THANK YOU" FOR REMAINING TRUE TO WHAT YOUR HEART HAS TOLD YOU.

THANK YOU.

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