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BANQUET PRESENTATION

BY

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CAMPAIGN 88
SURGEON GENERAL'S CONFERENCE

BUILDING COMMUNITY-BASED SERVICE SYSTEMS
FOR
CHILDREN WITH SPECIAL HEALTH CARE NEEDS

WASHINGTON, D.C.

SEPTEMBER 7, 1988

WELCOME.

GOOD EVENING. I AM DELIGHTED TO WELCOME ALL OF YOU TO THE SURGEON GENERAL'S CONFERENCE ON COMMUNITY-BASED SERVICE SYSTEMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS. I AM ESPECIALLY HAPPY TO SEE SUCH A LARGE GROUP OF PARTICIPANTS, -- THERE ARE WELL OVER A THOUSAND, -- REPRESENTING DOZENS OF ORGANIZATIONS FROM ALL OVER THE COUNTRY. THE OVERWHELMING INTEREST IN THIS MEETING IS HEARTENING -- NOT ONLY TO ME, BUT TO OUR SPONSORS AND CO-SPONSORS AS WELL.

THIS CONFERENCE BRINGS TOGETHER PUBLIC AND PRIVATE HEALTH CARE PROVIDERS FROM A VARIETY OF DISCIPLINES, PUBLIC AND PRIVATE PROVIDERS OF SOCIAL SERVICES, MENTAL HEALTH SERVICES, SPECIAL EDUCATION, VOCATIONAL AND FAMILY SUPPORT SERVICES, AS WELL AS PARENTS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND COMMUNITY LEADERS. IN ADDITION, MAJOR PROFESSIONAL ORGANIZATIONS, PARENT ORGANIZATIONS, AND ORGANIZATIONS OF ADMINISTRATORS OF PUBLIC PROGRAMS ARE SERVING AS CO-SPONSORS OF THIS CONFERENCE. I HOPE THAT OVER THE COURSE OF THIS THREE DAY MEETING, YOU WILL HAVE THE OPPORTUNITY TO SEE MANY "OLD" FRIENDS AND COLLEAGUES, AS WELL AS MAKE NEW FRIENDSHIPS.

THE KIDS ON THE BLOCK

NOW I'D LIKE TO INTRODUCE YOU TO BARBARA AIELLO, THE FOUNDER OF THE KIDS ON THE BLOCK, WHO WILL INTRODUCE YOU TO SOME SPECIAL NEW FRIENDS!

PRESENTATION OF KIDS ON THE BLOCK

I WOULD LIKE TO SHARE WITH YOU MY THOUGHTS ON WHY THIS MEETING IS SUCH AN IMPORTANT STEP IN OUR CONTINUING EFFORTS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES.

THOSE OF YOU WHO ATTENDED THE GALA CELEBRATION AT THE KENNEDY CENTER ON THE OCCASION OF THE 25TH ANNIVERSARY OF THE DIVISION OF MATERNAL AND CHILD HEALTH OF THE PUBLIC HEALTH SERVICE WILL REMEMBER THAT I HUNG THE SURGEON GENERAL'S MEDALLION AROUND THE NECKS OF VINCE HUTCHINGS AND KATHERINE BAIN FOR THEIR CONTRIBUTIONS TO THE OFFICE OF THE SURGEON GENERAL AND TO THIS SURGEON GENERAL IN PARTICULAR.

TONIGHT I WOULD LIKE TO HONOR THREE INDIVIDUALS WITH ONE OF THE THREE VERSIONS OF THE HIGHEST AWARD THAT I CAN PERSONALLY GIVE. WILL MERLE MCPHERSON, PHILLIS MCGRAB, AND EARL BREWER PLEASE COME FORWARD AND JOIN ME AT THE LECTERN.

MERLE MCPHERSON HAS BEEN A CONSTANT RESOURCE, CRITIC, MANAGER AND ORGANIZER OF MY EFFORTS IN THE CARE OF HANDICAPPED CHILDREN AND THEIR FAMILIES.

PHILLIS MCGRAB MAKES ME CRY WHENEVER I'M WITH HER. SHE IS NOT AS EMOTIONALLY DEVASTATING AS YOU MIGHT THINK. SHE WEARS MUSK PERFUME AND I'M ALLERGIC TO MUSK. HOWEVER PHILLIS, IN THE PRIVATE SECTOR HAS BEEN ANOTHER MERLE MCPHERSON TO ME.

EARL BREWER HAS BEEN A SAGE COUNSELOR, A MOVER AND A SHAKER (FREQUENTLY BEHIND THE SCENES), AND A TRUE BELIEVER IN COMMUNITY BASED HEALTH SERVICES FOR SPECIAL NEEDS CHILDREN. I ESPECIALLY APPRECIATE THE FACT THAT EARL MADE THE TREMENDOUS EFFORT TO BE WITH US HAVING JUST HAD A TRAGEDY IN HIS FAMILY. HE AND I HAVE MANY THINGS IN COMMON, BUT NOW WE SHARE THE BOND THAT EXISTS BETWEEN MEN WHO HAVE LOST A GROWN CHILD.

I MIGHT ADD THAT THE FACT THAT THESE THREE WERE MY EUROPEAN TRAVELING COMPANIONS AS WE EXPLORED COMMUNITY BASED HEALTH SERVICES FOR SPECIAL NEEDS CHILDREN HAS NOTHING TO DO WITH THEIR RECOGNITION TONIGHT.

THE CITATIONS ALL READ THE SAME AND THAT SAVED SOME OF MY CREATIVE TALENT FOR YET ANOTHER DAY.

THIS IS THE SURGEON GENERAL'S EXEMPLARY SERVICE AWARD AND IS PRESENTED TO EACH FOR EXEMPLARY CONTRIBUTIONS TO THE CARE OF CHILDREN WITH SPECIAL HEALTH NEEDS THROUGH THE NATIONAL PROMOTION OF COMPREHENSIVE FAMILY CENTER SERVICES. SEPTEMBER 7, 1988.

AS A PARENT, THEN AS A PEDIATRIC SURGEON, AND AS SURGEON GENERAL FOR THE PAST 7 YEARS, I HAVE HAD A COMMITMENT TO THESE CHILDREN AND THEIR FAMILIES FOR ALMOST HALF A CENTURY. IN 1982, AS ONE OF THE FIRST THINGS I DID IN GOVERNMENT, I CONVENED A SURGEON GENERAL'S WORKSHOP ON CHILDREN WITH HANDICAPS AND THEIR FAMILIES. THIS WORKSHOP RESULTED IN MAJOR RECOMMENDATIONS FOR IMPROVING SYSTEMS OF CARE AND FINANCING OF CARE. MANY OF THE WORKSHOP RECOMMENDATIONS WERE SUCCESSFULLY IMPLEMENTED, ESPECIALLY AS REGIONAL, STATE, AND LOCAL CONFERENCES FOLLOWED. A CATALOG OF THE WIDE VARIETY OF SUBSEQUENT CONFERENCES, WORK GROUPS, GRANTS, NETWORKS, PUBLICATIONS, AND OTHER PROJECTS, NOT ONLY FILLED A LARGE VOLUME, BUT DEMONSTRATED THE TREMENDOUS INTEREST AND CONCERN OF FAMILIES AND PROFESSIONALS INVOLVED IN THE CARE OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

LAST YEAR (JUNE 1987), I CONVENED THE SURGEON GENERAL'S CONFERENCE ON CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN HOUSTON. THIS MEETING WAS A "CALL TO ACTION" TO CREATE A NATIONAL AGENDA TO IMPROVE THE LIVES OF THESE YOUNGSTERS AND THEIR FAMILIES. THE THEME OF THE CONFERENCE WAS A FAMILY-CENTERED, COMMUNITY-BASED, COORDINATED APPROACH TO HEALTH CARE. THERE I PRESENTED THE SURGEON GENERAL'S REPORT ON CHILDREN WITH SPECIAL HEALTH CARE NEEDS, WHICH CONTAINED SEVEN ACTION STEPS TO IMPROVE ACCESS TO CARE AND QUALITY OF LIFE FOR THESE CHILDREN AND THEIR FAMILIES.

ONE OF THESE ACTION STEPS IS TO BUILD COMMUNITY-BASED SERVICE SYSTEMS. THIS ACTION STEP REALLY ENCOMPASSES ALL THE OTHERS. IF WE BUILD STRONG COMMUNITY-BASED SYSTEMS OF CARE, THEN WE HAVE DEMONSTRATED OUR COMMITMENT TO THESE CHILDREN AND THEIR FAMILIES. ADEQUATE PREPARATION OF PROVIDERS OF CARE IS ESSENTIAL FOR FLEXIBLE, RESPONSIVE COMMUNITY-BASED SYSTEMS. COALITIONS OF PARENTS, PROFESSIONALS FROM MANY DISCIPLINES, AND PUBLIC, PRIVATE, AND VOLUNTARY ORGANIZATIONS HELP ENSURE SUCCESSFUL DELIVERY OF COMMUNITY-BASED SERVICES.

FURTHERMORE, STUDIES HAVE SHOWN THAT A COMPREHENSIVE, COORDINATED APPROACH TO CARE IS COST-EFFECTIVE. WE CAN CONTROL COSTS WHILE ENSURING QUALITY OF SERVICES. WE HAVE DEMONSTRATED THE FEASIBILITY OF THIS WITH SPECIFIC DISEASES AND CONDITIONS. OUR CHALLENGE IS TO USE THIS EXPERIENCE TO DEVELOP SYSTEMS OF GENERIC SERVICES AT THE COMMUNITY LEVEL. IN ADDITION, ALL CHILDREN AND THEIR FAMILIES SHOULD HAVE ACCESS TO ADEQUATE HEALTH INSURANCE. AND, HEALTH CARE INSURANCE MUST ADEQUATELY COVER CHRONIC CARE AND CARE IN THE COMMUNITY.

FINALLY, THROUGH CONTINUING RESEARCH AND DISSEMINATION OF INFORMATION, WE WILL EXPAND OUR KNOWLEDGE. BUT RESEARCH AND INFORMATION ARE WORTHLESS IF WE DO NOT PUT INTO PRACTICE WHAT WE LEARN. WE NEED TO IMPLEMENT NEW IDEAS THAT WILL DEVELOP AND IMPROVE SYSTEMS OF COMMUNITY-BASED, FAMILY-ORIENTED CARE.

WHO ARE THESE CHILDREN?

CHILDREN WITH SPECIAL HEALTH CARE NEEDS ARE CHILDREN WITH HEALTH PROBLEMS, REQUIRING SOMETHING BEYOND ROUTINE CARE. THEY ARE CHILDREN WITH ACTUAL OR POTENTIAL DISABILITIES AND/OR CHRONIC ILLNESS. THEY ARE ALSO CHILDREN WITH ACTUAL OR POTENTIAL HEALTH-RELATED EDUCATIONAL AND BEHAVIORAL PROBLEMS.

WHY BUILD COMMUNITY-BASED SERVICE SYSTEMS?

COMMUNITY-BASED SERVICE SYSTEMS ARE GENERALLY DEFINED AS ORGANIZED NETWORKS OF INTEGRATED AND COORDINATED SERVICES AT THE LOCAL LEVEL. THESE SYSTEMS ARE NEEDED BECAUSE THESE CHILDREN AND THEIR FAMILIES REQUIRE A VARIETY OF SERVICES FROM MANY DIFFERENT KINDS OF PROFESSIONALS AND AGENCIES. SUCH SERVICES ARE OFTEN HIGHLY FRAGMENTED. IT IS OUR CHALLENGE TO ENSURE THAT THESE CHILDREN AND THEIR FAMILIES RECEIVE THE COMPREHENSIVE SERVICES THEY NEED IN A TIMELY, CONSISTENT MANNER. WE MUST RECOGNIZE THAT THE SERVICES NEEDED BY THESE CHILDREN AND THEIR FAMILIES ALL TOO OFTEN ARE NOT AVAILABLE OR ACCESSIBLE IN OR NEAR THEIR COMMUNITIES. BY DELIVERING NEEDED SERVICES AT THE LOCAL LEVEL, WE CAN PROMOTE NORMAL PATTERNS OF LIVING FOR CHILDREN AND FAMILIES. BUT, AS WE BUILD THESE SYSTEMS OF SERVICES, WE MUST ALSO ENSURE THAT THEY RESPOND TO THE NEEDS OF CHILDREN AND THEIR FAMILIES, RATHER THAN REQUIRING THEM TO ADAPT TO THE SYSTEM.

(THE ROLE OF HEALTH IN A COMMUNITY-BASED SYSTEM)

A SYSTEM OF COMMUNITY-BASED SERVICES MUST PROVIDE ACCESS TO COMPREHENSIVE SERVICES -- HEALTH, EDUCATIONAL, VOCATIONAL, EARLY INTERVENTION, MENTAL HEALTH, SOCIAL SERVICES, FAMILY SUPPORT, AND MANY OTHERS. AS A PEDIATRICIAN, I AM WELL AWARE OF THE CRITICAL ROLE THAT HEALTH SERVICES PLAY IN A COMMUNITY-BASED SERVICE SYSTEM. WITHOUT HEALTH SERVICES, THE SYSTEM IS CRIPPLED. HEALTH PROFESSIONALS HAVE KNOWLEDGE AND EXPERIENCE THAT ARE ESSENTIAL TO PROFESSIONALS IN OTHER FIELDS AND VICE VERSA. WE MUST DEVELOP AND EXPAND COLLABORATIVE RELATIONSHIPS BETWEEN HEALTH PROFESSIONALS AND PROFESSIONALS IN OTHER SECTORS TO ASSURE THAT CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES RECEIVE HIGH QUALITY COMPREHENSIVE SERVICES. CONCERNS ABOUT TURF SHOULD NOT ENTER THE EQUATION.

(PULLING IT ALL TOGETHER)

THIS MEETING HAS BROADENED OUR CONSTITUENCY CONSIDERABLY. THE COMMITMENT TO IMPROVING THE WELFARE OF THESE CHILDREN AND THEIR FAMILIES IS ILLUSTRATED BY THE MANY ORGANIZATIONS THAT ARE CO-SPONSORING THIS CONFERENCE. I CANNOT RECOGNIZE ALL 77 AT THIS TIME. BUT MY UNDERSTANDING OF AND APPRECIATION FOR THEM IS INDICATED BY THE FACT THAT I WORKED WITH 12 OF THEM BEFORE COMING INTO GOVERNMENT AND THERE ARE 37 GROUPS THAT I WORK WITH NOW, MANY BEING EXTENSIONS OF MY FORMER INCARNATION AS A PEDIATRIC SURGEON. THANK YOU ALL!

THE SURGEON GENERAL'S CALL TO ACTION LAST YEAR ESTABLISHED A NATIONAL AGENDA TO ASSURE THAT THIS COUNTRY HAS A COMMUNITY BASED, FAMILY-CENTERED, COORDINATED APPROACH TO CARE FOR ALL CHILDREN WITH SPECIAL HEALTH CARE NEEDS. THIS CONFERENCE SHOULD AND I AM CONFIDENT WILL MAKE THAT NATIONAL AGENDA AND SHOW HOW TO MAKE IT A REALITY. WE ARE MOVING FORWARD! THIS MEETING IS AN IMPORTANT MILESTONE IN THE ONGOING PROCESS OF CREATING SOUND, EFFECTIVE COMMUNITY-BASED SYSTEMS.

AND NOW, A PERSONAL NOTE. ALTHOUGH I DO NOT EXIT WITH THIS ADMINISTRATION, IT IS RATHER UNLIKELY THAT I WILL BE AROUND TO CONVENE ANOTHER CONFERENCE LIKE THIS ONE.

WE HAVE LEARNED A GREAT DEAL AND WE STILL HAVE MUCH TO LEARN. NOW I MUST LAY A CHARGE ON YOU: WHAT WE HAVE LEARNED AND WILL LEARN MUST BE SHARED. I'M COUNTING ON YOU TO DO THAT AS YOU CONTINUE TO BUILD COMMUNITY-BASED SERVICE SYSTEMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND EXPAND THE CONCEPT NATIONWIDE.

THIS CANNOT BE DONE WITHOUT THE COMMITMENT AND DETERMINATION OF ALL THE CHILDREN, FAMILIES, GOVERNMENT OFFICIALS, AND PROVIDERS WHO HAVE BROUGHT US TO THIS POINT. WHY NOT INVITE ME BACK IN A YEAR OR TWO AND SHOW ME WHAT YOU HAVE DONE? IN THE MEANTIME, REMEMBER, I'LL BE WATCHING!

ENJOY THE CONFERENCE. THANK YOU.