

KEYNOTE AND WELCOME

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PREVENTION SHOWCASE AND FORUM

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(GREETINGS TO HOSTS, GUESTS, ETC.)

THE PROGRAM FOR THE INTERNATIONAL SUMMIT AND FOR THIS NATIONAL SHOWCASE AND FORUM GIVE AMPLE TESTIMONY TO OUR CONTINUED COMMITMENT TO LEARN MORE ABOUT MENTAL RETARDATION AND, TO THE EXTENT POSSIBLE, PREVENT ITS OCCURRENCE. SINCE THE LAST SUMMIT, SOME FIVE YEARS AGO, THE RESEARCH COMMUNITY AND THE HEALTH CARE AND SOCIAL SERVICES COMMUNITY HAVE MADE TREMENDOUS STRIDES IN EXPANDING OUR KNOWLEDGE BASE AND IN EXTENDING OUR RANGE OF SERVICE OPTIONS.

I THINK WE ARE DOING A MUCH BETTER JOB THAN EVER BEFORE IN RESEARCH AND IN PROVIDING ASSISTANCE TO THE MENTALLY RETARDED AND THEIR FAMILIES. WE HAVE EVERY REASON TO BE HOPEFUL AND TO BE OPTIMISTIC...BUT WITH A TOUCH OF CAUTION NEVERTHELESS.

MENTAL RETARDATION STILL POSES MORE QUESTIONS THAN WE HAVE ANSWERS. ITS BASIC MECHANISMS ARE STILL WRAPPED IN MYSTERY. AND AS WE CONTINUE TO PROBE, WE ARE SOMETIMES OVERWHELMED BY THE IMPLICATIONS OF THE FIELD OF STUDY BEFORE US. THIS SINGLE AREA OF RESEARCH AND STUDY CAN REVEAL SO MUCH TO US OF THE NATURE OF THE HUMAN CONDITION -- THE COMPLEXITY...AND THE JOY...AND THE BURDEN.

THINKING ABOUT THIS ASPECT OF OUR WORK, I WAS REMINDED OF THE REMARK BY THE PHILOSOPHER WILLIAM JAMES. HE TRIED TO SEARCH BEYOND THE BRIGHT FACE THAT MOST PEOPLE PRESENT TO THE WORLD. JAMES FELT THAT "IN THE DEEPEST HEART OF ALL OF US THERE IS A CORNER IN WHICH THE ULTIMATE MYSTERY OF THINGS WORKS SADLY."

FOR CENTURIES, WHEN CONFRONTED BY MENTAL RETARDATION, PEOPLE HAVE BEEN PUZZLED, FRUSTRATED, AND SADDENED. GRADUALLY, OVER TIME, THOSE FEELINGS HAVE BEEN CHANGING. TODAY, EVEN THOUGH WE STILL HAVE MUCH TO LEARN ABOUT ABOUT MENTAL RETARDATION, WE ARE FAR MORE UNDERSTANDING AND ACCEPTING OF THE MENTALLY RETARDED. WHAT'S MORE, WE NOW THINK IN TERMS OF THEIR INTEGRATION INTO THE NORMAL LIFE OF OUR SOCIETY.

FROM MY READING OF THE PROCEEDINGS OF THE FIRST INTERNATIONAL SUMMIT, I THINK THIS FEELING WAS EVIDENT IN 1977. IT IS CERTAINLY WITH US TODAY. IT IS ALSO EVIDENT IN THE WAY THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION APPROACHED ITS 1981 ANNUAL REPORT TO THE PRESIDENT. I LIKE THE POSITIVE, WELL-DOCUMENTED CASE MADE IN THAT REPORT FOR GREATER INTEGRATION OF MENTALLY RETARDED PERSONS INTO THE AMERICAN WORKFORCE. AS SECRETARY SCHWEIKER SAYS, "GIVEN TRAINING AND EMPLOYMENT, RETARDED CITIZENS, ONCE THOUGHT OF AS BEING DEPENDENT FOR LIFE, CAN REACH INCREASED LEVELS OF SOCIAL AND ECONOMIC INDEPENDENCE, WHICH MAY EQUAL THOSE OF AVERAGE CITIZENS."

THE 1981 REPORT OF THE P.C.M.R. IS ONE EXAMPLE OF OUR COMMITMENT TO BRING MORE OF OUR MENTALLY RETARDED CITIZENS INTO THE MAINSTREAM OF AMERICAN LIFE. FORTUNATELY IT IS NOT THE ONLY EXAMPLE. THIS THEME CAN BE READ IN A VARIETY OF REPORTS OF WHAT GOVERNMENT HAS BEEN DOING AS WELL AS WHAT IT HOPES TO GET DONE. JUST SUCH A DOCUMENT THAT POINTS TO THE FUTURE IS THE FIVE-YEAR RESEARCH PLAN FOR THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT.

OF THE 15 RESEARCH GOALS FOR MENTAL RETARDATION IN THAT PLAN, FOUR ARE DEDICATED TO "AMELIORATION AND REHABILITATION." WE HOPE THAT THE NEW KNOWLEDGE DEVELOPED UNDER THIS HEADING SHOULD FURTHER ENABLE RETARDED PERSONS TO MAKE "AN OPTIMAL ADJUSTMENT TO COMMUNITY LIFE," IN THE WORDS OF THE N.I.C.H.D. RESEARCH STEERING COMMITTEE.

THOSE ARE VERY ENCOURAGING WORDS. THEY DEMONSTRATE THAT THE MARRIAGE BETWEEN THE BIOMEDICAL AND THE BEHAVIORAL SCIENCES IS NOT ONLY INTACT BUT IT IS BEING CONTINUALLY STRENGTHENED BY THE INSTITUTE, ITS CONTRACTORS, AND ITS GRANTEES. GRANTED, THERE IS STILL MUCH THAT WE NEED TO LEARN ABOUT DOWN SYNDROME AND THE "FRAGILE X" SYNDROME, ABOUT CYTOGENETICS AND DEVELOPMENTAL NEUROLOGY. BUT A HUMAN BEING IS MUCH MORE THAN JUST A "GENETIC AGGREGATE" OR A NETWORK OF INFORMATION TRANSMISSION SYSTEMS.

THE LATE DR. RENE DUBOS WROTE THAT "EACH HUMAN BEING IS UNIQUE, UNPRECEDENTED, UNREPEATABLE." BUT DUBOS WAS EVEN MORE SPECIFIC. HE SAID WE RECOGNIZED EACH UNIQUE HUMAN BEING "BY HIS VOICE, HIS FACIAL EXPRESSIONS, AND THE WAY HE WALKS -- AND EVEN MORE BY HIS CREATIVE RESPONSES TO SURROUNDINGS AND EVENTS." IN OTHER WORDS, PEOPLE DO INTERACT WITH THEIR HUMAN AND PHYSICAL ENVIRONMENTS...AND THE WAY THEY INTERACT TELLS US A GREAT DEAL ABOUT WHO THEY ARE.

THIS LEVEL OF SENSITIVITY LIES MUCH CLOSER TO THE SOURCE OF THE "MYSTERIES" WE PURSUE IN MEDICINE, WHAT DUBOS CALLS "THE SCIENCE OF HUMAN LIFE." FORTUNATELY, OUR COLLEAGUES IN THE N.I.C.H.D. ARE AWARE

OF THAT AND THE PRESIDENT'S COMMITTEE KNOWS IT, TOO. HOW IMPORTANT THAT UNDERSTANDING IS FOR THE FUTURE...THE DECADES AHEAD...WHEN SOCIETY WILL GARNER THE BENEFITS OF TODAY'S RESEARCH AND DETECTION SERVICES FOR THE MENTALLY RETARDED.

I AM EMPHASIZING THE BIOBEHAVIORAL ASPECT OF RESEARCH AND SERVICE BECAUSE THAT'S THE BASIS UPON WHICH A GREAT DEAL OF OUR PREVENTION EFFORT IS MOUNTED. IT MORE CLOSELY REFLECTS THE TOTAL HUMAN EXPERIENCE. FOR EXAMPLE, IF WE IDENTIFY A LINK BETWEEN CERTAIN MATERNAL NUTRITION DEFICITS AND THE APPEARANCE OF MENTAL RETARDATION IN OFF-SPRING, HOW THEN DO WE CONVINCE PREGNANT WOMEN TO MAINTAIN A CERTAIN NUTRITIONAL BALANCE IN THEIR DIET? AGAIN, AFTER WE IDENTIFY THE LINK BETWEEN HERPES AND INJURY TO THE DEVELOPING FETUS, HOW DO WE BREAK THE CHAIN OF HERPES TRANSMISSIONS AMONG POTENTIAL PARENTS?

THESE QUESTIONS -- AND MANY OTHERS LIKE THEM -- PRESENT BOTH A BIOMEDICAL AND THE BEHAVIORAL CHALLENGE TO THE PUBLIC HEALTH PRACTITIONER, PARTICULARLY THOSE OF US CONCERNED WITH THE RETARDED.

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES, WITH THE STRONG SUPPORT OF THE PRESIDENT, IS PURSUING THIS TYPE OF OVERALL PREVENTION AND HEALTH PROMOTION STRATEGY. WHILE SOME ELEMENTS OF THE STRATEGY MAY BE MORE APPROPRIATE FOR THE AGED OR FOR ADOLESCENTS, A NUMBER OF ELEMENTS DIRECTLY RELATE TO THE PREVENTION OF MENTAL RETARDATION OR TO PREVENTING OR CONTROLLING THE STRESSES THAT MAY OCCUR AMONG A RETARDED PERSON'S FAMILY.

IT IS NOT COMMON THESE DAYS TO FIND A GOVERNMENT PROGRAM THAT IS NEW AND IS ALSO EXPANDING. YET, THAT IS THE NATURE OF THE COMMITMENT THAT THE PREVENTION PROGRAM HAS IN OUR DEPARTMENT. AS YOU KNOW, THE ESSENTIAL STRENGTH OF THE RESEARCH EFFORT IN THE PUBLIC HEALTH SERVICE IS BEING MAINTAINED. THAT EFFORT, HOWEVER, ALSO INCLUDES THE DEVELOPMENT OF NEW KNOWLEDGE RELATED TO PREVENTION.

LET ME AMPLIFY THAT STATEMENT WITH THE FOLLOWING FEW NUMBERS:

- o THE RESEARCH BUDGET FOR THE NATIONAL INSTITUTES OF HEALTH IS PROJECTED TO RISE BY ABOUT \$109 MILLION IN FISCAL 1983, PROVIDING CONTINUED STRONG SUPPORT FOR BIOMEDICAL AND SOME BEHAVIORAL RESEARCH...
- o THE RESEARCH BUDGET FOR THE ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION, WHERE MOST OF OUR BEHAVIORAL AND SOME OF OUR BIOMEDICAL RESEARCH IS CARRIED ON, IS PROJECTED TO RISE ABOUT \$27 MILLION IN THE NEXT FISCAL YEAR...
- o BUT ALL RESEARCH, SERVICE, AND INFORMATION ACTIVITIES COMBINED THAT ARE RELATED TO THE PREVENTION INITIATIVE WILL RISE ABOUT \$870 MILLION, A 4.5 PERCENT INCREASE OVER LAST YEAR -- AND THIS ALL COMES AT A TIME WHEN MOST FEDERAL ACTIVITIES ARE BEING HELD AT PRESENT LEVELS OR BEING TRIMMED TO LOWER, SMALLER LEVELS.

THE CLEAR MESSAGE FROM THIS SHOULD BE THAT THE ADMINISTRATION IS TRULY PUTTING ITS MONEY WHERE ITS RHETORIC IS.

SECRETARY SCHWEIKER PROMISED THAT, UNDER HIS STEWARDSHIP OF OUR DEPARTMENT, PREVENTION WOULD BE PUT AT THE VERY TOP OF THE FEDERAL HEALTH AGENDA. AND HE'S DONE EXACTLY THAT. HE HAS ALSO INVITED THE PRIVATE SECTOR -- NON-PROFIT AND PROFIT-MAKING ORGANIZATIONS ALIKE -- TO JOIN IN AND HELP. AND THERE IS ALREADY A GROWING LIST OF PROFESSIONAL, VOLUNTARY, AND TRADE ASSOCIATIONS THAT ARE TAKING PART IN THIS TRULY NATIONAL STRATEGY OF PREVENTION AND HEALTH PROMOTION.

AS FOR MATERNAL AND CHILD HEALTH IN PARTICULAR, THE PUBLIC HEALTH SERVICE IS ONE OF MORE THAN 50 NATIONAL ORGANIZATIONS WHO HAVE JOINED TOGETHER IN A NATIONWIDE PROGRAM CALLED "HEALTHY MOTHERS, HEALTHY BABIES." THIS UNUSUAL COALITION IS FOLLOWING A SIX-POINT PROGRAM EMPHASIZING PRENATAL CARE, GOOD NUTRITION, AND GOOD FOLLOW-THROUGH FOR MEDICAL AND SOCIAL SERVICES AS MAY BE REQUIRED FOLLOWING DELIVERY.

BY 1985, WITH THE HELP OF THE "HEALTHY MOTHERS, HEALTHY BABIES" PROGRAM AND OTHER EFFORTS AROUND THE COUNTRY, WE HOPE TO ACHIEVE TWO IMPORTANT GOALS. I THINK THEY ARE OF SPECIAL IMPORTANCE TO THIS MEETING. THEY ARE...

* ...TO INCREASE THE AWARENESS OF WOMEN OF CHILDBEARING AGE OF THE RISKS TO PREGNANCY ASSOCIATED WITH SMOKING, INCLUDING THE RISKS OF LOWER BIRTH WEIGHT, SPONTANEOUS ABORTION, AND FETAL DEATH...

* ...AND TO INCREASE THE PROPORTION OF WOMEN OF CHILDBEARING AGE WHO ARE AWARE OF THE RISKS ASSOCIATED WITH PREGNANCY AND DRINKING, IN PARTICULAR THE RISK OF DELIVERING A CHILD EXHIBITING "FETAL ALCOHOL SYNDROME."

BUT SMOKING AND IMMODERATE DRINKING ARE NOT THE ONLY PREVENTABLE AGENTS ADVERSELY AFFECTING A PREGNANCY. OTHER ENVIRONMENTAL FACTORS MAY COME INTO PLAY AS WELL: TOXIC AGENTS IN THE HOME OR WORK PLACE, LEAD LEVELS IN THE AIR, AND CERTAIN POTENTIAL CONTAMINANTS OF DRINKING WATER ARE OTHERS. INFECTIOUS DISEASES, INCLUDING THE WHOLE RANGE OF SEXUALLY TRANSMITTED DISEASES, ARE OTHER FACTORS. ACCIDENTS SUFFERED BY THE PREGNANT WOMAN WHILE RIDING IN A CAR OR WHILE AT WORK -- OR ANY SERIOUS PHYSICAL TRAUMA, FOR THAT MATTER -- MAY ALSO HAVE AN ADVERSE EFFECT, CAUSING RETARDATION OF THE INFANT. AND THE RESEARCH IS CONTINUING REGARDING THE EFFECTS OF GENETIC FACTORS, PREMATUREITY, FAMILY POVERTY, AND METABOLIC DISORDERS.

NOT ALL THESE CAN BE PREVENTED. I WOULD GO EVEN FURTHER AND SAY THAT PROBABLY NONE CAN BE PREVENTED BY THE GOVERNMENT, ALTHOUGH FEDERAL ACTION MAY WELL EXERT A STRONG INFLUENCE ON OUTCOMES. I'M THINKING, FOR EXAMPLE, OF THE GOVERNMENT INTEREST IN LEAD LEVELS IN THE AIR, IN MAXIMUM SPEED LIMITS ON INTERSTATE HIGHWAYS, IN STOPPING THE SPREAD OF INFECTIOUS DISEASES THROUGH MASS VACCINATION, OR IN MONITORING THE WORKPLACE FOR THE PRESENCE OF TERATOGENIC SUBSTANCES.

THAT MAY BE TRUE. BUT THE PRIMARY FEDERAL ROLE IS IN THE SUPPORT OF RESEARCH. AND IN THAT CASE, THE LEAD AGENCY WOULD APPEAR TO BE THE NATIONAL INSTITUTE FOR CHILD HEALTH AND HUMAN DEVELOPMENT. IN JUST FIVE DAYS THE N.I.C.H.D. WILL CELEBRATE ITS 20TH ANNIVERSARY. IN THE COURSE OF ITS LIFE SO FAR, THE INSTITUTE HAS MADE MANY CONTRIBUTIONS TO IMPROVE MATERNAL AND CHILD HEALTH IN GENERAL, AND SEVERAL SPECIFIC CONTRIBUTIONS FOR THE DETECTION, CONTROL, OR PREVENTION OF MENTAL RETARDATION.

IT'S APPROPRIATE TO MENTION HERE, I BELIEVE, THE DEVELOPMENT BY THE N.I.C.H.D. OF THE SIMPLE TEST IN THE NEWBORN FOR P.K.U., OR PHENYLKETONURIA. THANKS TO THIS SIMPLE TEST, MENTAL RETARDATION BROUGHT ON BY P.K.U. CAN NOW BE ROUTINELY PREVENTED THROUGH CAREFUL DIET MANAGEMENT. RECENTLY, N.I.C.H.D. RESEARCHERS ALSO DEVELOPED A SCREENING METHOD FOR CONGENITAL HYPOTHYROIDISM. NOW IT IS POSSIBLE TO SCREEN FOR P.K.U. AND HYPOTHYROIDISM AT THE SAME TIME WITH THE SAME DROP OF BLOOD. AT ONE TIME, THESE TWO CONDITIONS -- P.K.U. AND HYPOTHYROIDISM -- COMBINED WERE THE CAUSE OF ABOUT 300 CASES EACH YEAR OF MILD TO SEVERE MENTAL RETARDATION AMONG THE NEWBORN. BOTH CAUSES ARE NOW PREVENTABLE AND TREATABLE.

IN THE PAST FEW MINUTES I THINK I'VE TOUCHED, DIRECTLY OR INDIRECTLY, ON MOST OF THE MAJOR PREVENTION ACTIVITIES AVAILABLE TO US:

* IMPROVED PRENATAL CARE...

- * SPECIFIC ATTENTION TO THE SPECIAL NEEDS OF THE PREMATURE...
- * APPROPRIATE GENETIC COUNSELING...
- * IMMUNIZATION, ESPECIALLY RUBELLA...
- * AND THE PREVENTION OF FETAL ALCOHOL SYNDROME.

I DID NOT MENTION -- BUT I AM AWARE OF -- THE NEED TO GUARD AGAINST HEAD INJURIES TO CHILDREN, WHICH MEANS THE PREVENTION OR, AT LEAST, THE REDUCTION OF ACCIDENTS, PLUS ADDITIONAL ATTENTION TO THE PROBLEM OF CHILD ABUSE OR KERNICTERUS PREVENTION WITH IMMUNOGLOBULIN AFTER APPROPRIATE TESTS FOR RH ANTIBODIES.

ALTHOUGH THERE IS A WEALTH OF MATERIAL, ALREADY WIDELY PUBLISHED, ON THE DETECTION AND IDENTIFICATION OF MENTAL RETARDATION AMONG THE NEWBORN AND WHAT WE CAN DO ABOUT IT, THERE IS STILL VERY LITTLE IN THE LITERATURE THAT DEALS WITH THE PROBLEMS OF PREVENTING OTHER KINDS OF DISABILITIES AND DISEASES FROM ATTACKING THE MENTALLY RETARDED CHILD OR ADULT. ADDED TO THIS IS THE FACT THAT WE STILL DO NOT FULLY UNDERSTAND HOW THE RETARDED AND THEIR FAMILIES RESPOND TO ALL THE USUAL LIFE-CYCLE EVENTS.

IT'S POSSIBLE THAT, ALONG THE WAY, WE MAY HAVE BEEN GUILTY OF COMPARTMENTALIZING OUR INTERESTS...OF MAINTAINING TOO NARROW AND TOO RIGID A FOCUS ON THE PREVENTION OF MENTAL RETARDATION PER SE. AS A RESULT, WE KNOW VERY LITTLE ABOUT REDUCING THE RISKS AND HEALTH

HAZARDS TO THE RETARDED PERSON WHO IS IN THE MIDST OF LIFE. I THINK WE MAY HAVE MISSED EXPLORING FURTHER THIS "SCIENCE OF HUMAN LIFE," ABOUT WHICH RENE DUBOS WROTE SO ELOQUENTLY. IN THE NEXT FEW MINUTES I'D LIKE TO TALK ABOUT THIS PARTICULAR ASPECT OF THE PREVENTION CHALLENGE...A CHALLENGE THAT IS JUST BEGINNING TO TAKE SHAPE ON THE RESEARCH HORIZON.

A FEW MOMENTS AGO, I MENTIONED THAT ONE OF OUR MAIN GOALS SHOULD CONTINUE TO BE THE INTEGRATION, TO THE EXTENT POSSIBLE, OF THE MENTALLY RETARDED INTO THE MAINSTREAM OF AMERICAN LIFE. I SAY "TO THE EXTENT POSSIBLE" BECAUSE WE MUST ACKNOWLEDGE THE EXCEPTIONAL CHALLENGES PRESENTED BY THE SEVERELY OR PROFOUNDLY RETARDED -- CHALLENGES WHICH HAVE MORE TO DO WITH ELEMENTAL SURVIVAL THAN WITH SUCH ISSUES AS SOCIALIZATION OR THE QUALITY OF LIFE.

BUT, WITH JUST THAT ONE QUALIFICATION, WE NEED TO LOOK MORE CLOSELY AT THE KINDS OF RISKS THAT INTEGRATION ITSELF MAY PRESENT TO THE MILDLY RETARDED. THESE PERSONS ARE THE VAST MAJORITY, FORMING ABOUT 80 PERCENT OF THE RETARDED POPULATION. IT ALSO HAPPENS THAT A DISPROPORTIONATE NUMBER IS FOUND AMONG POPULATIONS DISADVANTAGED BY POVERTY OR GEOGRAPHY OR WHO HAVE BEEN VICTIMS OF RACIAL OR ETHNIC DISCRIMINATION. NEVERTHELESS, I THINK WE CAN -- AND WE SHOULD -- BEGIN NOW TO BUILD A NEW STRATEGY -- WHAT I WOULD CALL A "SECOND STRATEGY" -- OF PREVENTION THAT COULD BENEFIT RETARDED PERSONS AS THEY BECOME INTEGRATED INTO THE WORLD OF WORK, INTO THE LIFE OF THE FAMILIES THEY COME FROM, AND INTO THE LIVES OF THE FAMILIES THAT THEY THEMSELVES MAY CHOOSE TO FORM.

I ALSO THINK WE MIGHT REAP A KIND OF "BONUS" FROM THIS "SECOND STRATEGY" OF PREVENTION AND HEALTH PROMOTION. THAT BONUS WOULD BE THE POTENTIAL FOR REINFORCING A NUMBER OF IMPORTANT PREVENTION AND HEALTH PROMOTION CONCEPTS AMONG THE PEOPLE WHO EMPLOY OR IN SOME WAY SUPPORT THE RETARDED INDIVIDUAL. THEY, OF COURSE, ALSO REPRESENT A MUCH LARGER POPULATION.

LET ME OFFER THIS EXAMPLE:

WE KNOW THAT WEIGHT CONTROL IS IMPORTANT FOR THE RETARDED INDIVIDUAL, SINCE OBESITY CAN INTERFERE WITH WORK AND FAMILY LIFE AND INCREASE THE RISK OF CARDIOVASCULAR DISEASE. BUT OBESITY IS AS MUCH A HEALTH HAZARD TO THE PERSON WITH AN I.Q. OF LESS THAN 80 AS IT IS TO A PERSON WITH AN I.Q. OF 80 OR ABOVE. IF WE CAN DEVELOP NUTRITION PROGRAMS THAT ARE EFFECTIVE FOR THE RETARDED, ESTABLISHING DIET ROUTINES THEY WILL ACCEPT AND FOLLOW, I SHOULD IMAGINE THE RESULTS WOULD ALSO INFLUENCE AND BENEFIT THE CARE-TAKERS AND EMPLOYERS...THE VERY PEOPLE WHO WOULD RELAY THOSE PROGRAMS TO THE RETARDED.

BUT I DON'T WISH TO DWELL ON THIS. IT WOULD BE, AS I INDICATED, ONLY A BONUS. THE IMPORTANCE OF THIS "SECOND STRATEGY" IS QUITE SIMPLY WHAT IT CAN DO FOR THE RETARDED PERSON ALONE. IN ADDITION TO NUTRITION I BELIEVE WE NEED TO ADAPT OUR ENTIRE PREVENTION STRATEGY TO MEET THE NEEDS OF THE RETARDED INDIVIDUALS AND THEIR FAMILIES WHEREVER THAT CAN BE DONE:

- o WE NEED TO EMPHASIZE DENTAL HEALTH, PHYSICAL FITNESS, AND EXERCISE...
- o WE MUST BE VIGILANT REGARDING THE USE OF TOBACCO AND ALCOHOL...
- o WE MUST BE EQUALLY VIGILANT CONCERNING SEXUALLY TRANSMITTED DISEASE...
- o AND WE NEED TO WORK COOPERATIVELY WITH EMPLOYERS REGARDING SAFETY IN THE WORKPLACE.

I WILL ADMIT THAT THESE ARE EXTRAORDINARY CHALLENGES. FOR EXAMPLE, ONE OF THE MOST COMMON TENDENCIES AMONG THE RETARDED IS THEIR INABILITY TO IDENTIFY AND RESOLVE PROBLEMS, TO ORGANIZE INFORMATION IN A WAY THAT ISOLATES AND RESPONDS TO A PARTICULAR PROBLEM. THE RETARDED ALSO HAVE SERIOUS MEMORY DEFICITS, SHORTER ATTENTION SPANS, AND DIFFICULTY TRANSFERRING SKILLS AND BEHAVIORS FROM ONE ACTIVITY TO ANOTHER.

YOU KNOW THESE THINGS, OF COURSE. BUT I AM RE-STATING THEM HERE BECAUSE THEY ARE SKILLS THAT ARE DIRECTLY RELEVANT TO HEALTH PROMOTION AND THE PREVENTION OF DISEASE AND DISABILITY. AND THAT'S WHY THE CHALLENGE IS SO GREAT. NEVERTHELESS, I BELIEVE THAT IF WE COULD ACCOMPLISH THIS "SECOND STRATEGY" OF PREVENTION AMONG THE RETARDED, WE WOULD

AT THE SAME TIME LEARN A GREAT DEAL ABOUT HOW TO DELIVER THE ESSENCE OF OUR PREVENTION MESSAGE TO THE GENERAL PUBLIC. IN OTHER WORDS, WE MIGHT LEARN QUITE A FEW THINGS THAT WOULD MAKE OUR "FIRST STRATEGY" THAT MUCH MORE EFFECTIVE.

IN ADDITION, I BELIEVE WE NEED TO KNOW MORE ABOUT THE DYNAMICS WITHIN THE FAMILIES IN WHICH THERE IS A RETARDED INDIVIDUAL. I KNOW FROM PERSONAL OBSERVATION THAT THE OVERWHELMING MAJORITY OF THOSE FAMILIES ARE MADE UP OF LOVING AND DEEPLY CARING PEOPLE. BUT I ALSO KNOW THAT THEY OFTEN FUNCTION UNDER GREAT PERSONAL AND INTERPERSONAL STRESS...THAT THE SAME HIGH-RISK HEALTH ISSUES OF ALCOHOL, AUTO SAFETY, AND NUTRITION, FOR EXAMPLE, MAY BE AGGRAVATED FOR THOSE DEVOTED CARE-TAKERS.

WE HAVE CONCLUDED -- AND CORRECTLY, IN MY OPINION -- THAT AN INSTITUTIONAL ENVIRONMENT MAY BE A VERY POOR ANSWER FOR MOST MENTALLY RETARDED PERSONS. AND WE'VE GONE ON TO THE NEXT STEP. WE HAVE ENCOURAGED FAMILIES TO TAKE CARE OF THE MEMBERS WHO ARE RETARDED. WE'VE ASKED COMMUNITIES...NEIGHBORHOODS...TO BE ACCEPTING OF THESE HUMAN BEINGS. BUT WE PUBLIC HEALTH PROFESSIONALS HAVE NOT ALWAYS BEEN FORTHCOMING WITH THE KIND OF HELP THAT MAKES FAMILY LIFE REALLY LIVABLE WITH A RETARDED PERSON.

THESE ARE THINGS WE WILL KNOW MORE ABOUT, AS WE PUT MORE RESOURCES INTO LONGITUDINAL STUDIES, FOLLOWING RETARDED PERSONS THROUGH PERSONAL AND FAMILY LIFE-CYCLES, UNDERSTANDING THE HOME-TO-SCHOOL TRANSITIONS, THE SCHOOL-TO-WORK TRANSITIONS, KNOWING MORE ABOUT THEIR EFFORTS TO

REPLICATE FAMILY LIFE FOR THEMSELVES. AND IN THE COURSE OF REVIEWING THE RESULTS OF THESE LONG-TERM STUDIES, WE MIGHT VERY WELL BEGIN TO BUILD THE FRAMEWORK FOR THIS "SECOND STRATEGY." WE JUST MIGHT LEARN HOW TO HELP THE RETARDED TAKE ADVANTAGE OF THE SAME BASIC KNOWLEDGE OF PREVENTION AS THE GENERAL PUBLIC AND THUS ASSURE THEMSELVES OF AN ADDED DIMENSION TO THE QUALITY OF THEIR LIVES.

UNDERNEATH ALL THESE QUESTIONS AND CONCEPTS AND STRATEGIES I BELIEVE THERE IS A VERY POWERFUL IDEA THAT IS SHARED BY EVERYONE IN PUBLIC HEALTH. IT IS THE NOTION THAT EACH PERSON IS SPECIAL AND IS WORTH OUR VERY BEST...OUR MOST PROFESSIONAL...OUR MOST DEDICATED ATTENTION. KNOWING SOMEONE'S I.Q. LEVEL OR SOME OTHER SCORE MAY HELP US DETERMINE HOW WE MIGHT BEST DELIVER OUR INFORMATION OR OUR SERVICE. BUT THAT KNOWLEDGE CANNOT DETERMINE WHETHER WE WILL BE OF SERVICE. IT IS UNDERSTOOD THAT WE WILL BE OF SERVICE...AND THAT'S IMPORTANT.

THE GREAT SPANISH WRITER ORTEGA Y GASSETT PHRASED IT IN A SPECIAL WAY, AND I'D LIKE TO LEAVE IT WITH YOU THIS MORNING. HE SAID, "LIVING IS PRECISELY THE INEXORABLE NECESSITY TO MAKE ONESELF DETERMINATE, TO ENTER INTO AN EXCLUSIVE DESTINY..." I THINK WE IN MEDICINE AND PUBLIC HEALTH ACCEPT THE FACT THAT EVERY PERSON -- WHATEVER HIS OR HER I.Q. LEVEL OR MENTAL COMPETENCE -- EVERYONE HAS AN "EXCLUSIVE DESTINY," SOMETHING UNIQUE AND SPECIAL AND ONE'S OWN. IF I'M NOT MISTAKEN, THAT IS PROBABLY THE CORE OF THIS SECOND INTERNATIONAL SUMMIT AND NATIONAL SHOWCASE AND FORUM.

THANK YOU.

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