

REMARKS BY SENATOR HUBERT H. HUMPHREY

PCMR REUNION

September 23, 1971

It is a pleasure to meet again with one of the truly unique Presidential committees on the Washington scene -- as well as the alumni members of this distinguished group.

The President's Committee on Mental Retardation is just one of more than 2,000 special Presidential study and action groups that live in the half-light of bureaucracy. But this Committee is one that genuinely works and brings about progress.

This was so during the Johnson Administration, when the Committee began, It is true now during the Nixon Administration.

Without rancor, without loss of effectiveness, it has made the transition from one Administration to another, from one great political party's Administration to another. This, after all, is as it should be in matters that unite the concern of all Americans.

Mental retardation is not a selective affliction. Rich and poor, young and old, Democrat and Republican, conservative and liberal, male and female -- all may have occasion to experience it.

All may learn as Muriel and I did with our granddaughter, Vicky, the challenge that mental retardation can be to a family's strength and steadfastness -- how lonely the experience can be in the face of professional and public ignorance and apathy -- and how precious a personally accepted retarded child can be in the family circle.

So I am pleased that the President's Committee on Mental Retardation has continued its vigorous role, with the backing of the President and members of his Administration.

I have been pleased, too, by some of the recent government initiatives that cannot help but benefit the retarded, along with all handicapped people.

I also commend the Administration for getting behind the Developmental Disabilities program that Congress voted and for staying behind the various HEW and Labor Department programs in rehabilitation and employment of the handicapped.

Finally, but not least importantly, I congratulate the present membership of PCMR and executive director Joe Douglass on the imaginative "new thrust" program. This is an attempt to bring together in a unified initiative many of the endeavors of concern and effort that those involved with the mental retardation problem have been pursuing separately.

All of these programs must continue with steady, visible, persistent, often-repeated and action promoting support from the top, from the President of the United States. That is the only way that the momentum of the attack on mental retardation, built up through four national administrations, can be maintained.

It is the only way to assure that the wide spectrum of Federal agencies, with capability and authority to help the retarded and diminish the incidence of mental retardation, will indeed do something and will work together in the effort.

All of this is vital, because the fight against retardation will not be won in Washington. Washington can and must take the lead to help make victory possible. But the day-to-day fight will be waged and won as always on the local front -- in the great "out there" which all of us in government try to serve.

It will be won where teachers teach retarded children -- where researchers study the organic causes of mental retardation -- where parent associations toil to build community awareness and activities -- where regional center staffs counsel the retarded and organize programs to serve them -- where community action workers strive to overcome the conditions of deprivations that create so much of the mental retardation that exists in urban and rural America.

These are the front lines of the fight against mental retardation. And one of the continuing challenges of your Committee -- and all those who care about the retarded -- is to assure that the logistics effort works well and smoothly. It must assure that current knowledge reaches the public and those who can put it to use.

Stafford Warren, President Kennedy's assistant for mental retardation, maintained that the toll of mental retardation could be reduced by fully one half if all we know today could be applied successfully everywhere.

It is, of course, essential to plan, to study, to review, to analyze problems and programs for the retarded. But this is for naught, in my judgment, if all of this activity does not affect the lives of the mentally retarded and their families in a positive way.

In this country, we have become expert on studying, on planning, but too often we demonstrate little skill and action on implementation.

I know that every state has been encouraged to develop a plan for the mentally retarded. And these have been revised and upgraded from time to time with new types of plans.

At the same time we have had planning in rehabilitation, planning in welfare, planning in health. But all too frequently there has been no coordination between the plans and little thought given to real implementation.

The Developmental Disabilities Services Act holds great hope for pulling many groups together in common effort. It is a real milestone in legislation for all the handicapped. But this, too, calls for a plan.

And now the states will be spending so many hours coming up with massive paper work on planning that I am concerned about the time and energy they will have left. Will there be time left to implement bold, new innovative approaches for the care, training and rehabilitation of the mentally retarded?

There are some other concerns I would like to bring to your attention, too.

We talk a lot about decentralizing our residential facilities. Until we have sizeable demonstration funds to encourage the states to put this into action, I am afraid that not much progress will be made.

We need to change the standards for buildings in this country. For example, if we want to construct a small community-type residential building, we still have to meet old hospital standards based on the type of construction done 40 to 50 years ago. The Federal Government should lead the way in remedying this situation.

New types of residential facilities could come under housing standards as set by HUD rather than the hospital standards set by the Department of Health, Education, and Welfare. If we want to get the retarded into the mainstream of American life, they should live in home-like structures.

We should move more quickly into the field of accountability and evaluation of programs. I believe the day has passed when we can continually fund the same program year after year.

There should be a way to determine what is working and what is not working -- and there should be an on-going evaluation. Perhaps the Federal government could initiate bonus grants to those states and localities that do on-going, hard-nose evaluation.

We need a concentrated prevention research program that will be pinpointed by the Federal government. It is true that there is isolated research in some of the institutions. But we need a new focus program concentrated with one goal in mind -- prevention. Special emphasis should be given to the bio-medical, behavioral and deprivation areas.

We need to develop an advocate concept in the country. This would take in legal services and guardianship. This is particularly needed for those living in residential facilities without parents.

Several years ago the President's Committee recommended the establishment of a National Information Center. There have been reports made on this proposal, but there has been no real action. A National Information Center would make available vital retardation information not only to researchers, but also to other professionals and to consumers.

We need more discussion and soul-searching seminars on such issues as abortion and birth control. States are now grasping with these emotional issues. But is upon us now with breakthroughs in medical science on monitoring the fetus and predicting the likelihood of a mother bearing a handicapped child.

We need not only coordination, but many programs pulled together in the Department of HEW that deal with problems of the retarded and the developmental disabled. Very little has been done about coming up with an effective delivery system on the Federal level. Once we have a model delivery system, then the states could tailor their structure in a similar manner.

We need a strong recruitment program to encourage young people to work with the handicapped. We have scholarships available in some areas, but mostly on the graduate level.

We need to direct our efforts, especially to those young people who come from families that cannot afford to send them to college. This could be done through vigorous summer programs in facilities for the handicapped, where they work part-time and earn some money. The part-time work could actually be on a year-around basis through utilizing these young people on weekends and in evening work, such as community centers. Then those with the greatest ability could be given scholarship aid.

We need to give attention to facilities for the retarded juvenile offender and the disturbed retarded child. Perhaps some community based demonstration projects would provide us with some of the needed answers.

I know that all of you could make impressive additions to this list, too.

But I have one more suggestion. I would hope that the Committee would continue the effort that has been made today to keep former members fully informed, so that they can continue to assist in informal ways with the sizeable tasks that remain. They are a valuable resource. Do not overlook them.

And to you who have served previously on the Committee I urge you to keep abreast of the work of PCMR. Follow its work in your area of special concern. Prod them on if they are not moving fast enough or having the impact that you believe they should have.

I stand ready and willing to help and assure you of my support and devotion.

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PCMR REUNION

Crystal City Marriott
Arlington, Virginia

September 24, 1971

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PCMR REUNION
CRYSTAL CITY MARRIOTT
ARLINGTON, VIRGINIA
SEPTEMBER 24, 1971

IT IS A PLEASURE TO MEET AGAIN WITH ONE OF THE TRULY
UNIQUE PRESIDENTIAL COMMITTEES ON THE WASHINGTON SCENE --
AS WELL AS THE ALUMNI MEMBERS OF THIS DISTINGUISHED GROUP.

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION IS JUST
ONE OF MORE THAN 2,000 SPECIAL PRESIDENTIAL STUDY AND ACTION
GROUPS THAT LIVE IN THE HALF-LIGHT OF BUREAUCRACY, BUT THIS
COMMITTEE IS ONE THAT GENUINELY WORKS AND BRINGS ABOUT PROGRESS.

Kennedy +
THIS WAS SO DURING THE JOHNSON ADMINISTRATION^s, WHEN THE
COMMITTEE BEGAN. IT IS TRUE NOW DURING THE NIXON ADMINISTRATION.

WITHOUT RANCOR, WITHOUT LOSS OF EFFECTIVENESS, IT HAS
MADE THE TRANSITION FROM ONE ADMINISTRATION TO ANOTHER, FROM
ONE GREAT POLITICAL PARTY'S ADMINISTRATION TO ANOTHER. THIS,
AFTER ALL, IS AS IT SHOULD BE IN MATTERS THAT UNITE THE CONCERN
OF ALL AMERICANS.

L MENTAL RETARDATION IS NOT A SELECTIVE AFFLICTION. L RICH
AND POOR, YOUNG AND OLD, DEMOCRAT AND REPUBLICAN, CONSERVATIVE
AND LIBERAL, MALE AND FEMALE -- ALL MAY HAVE OCCASION TO
EXPERIENCE IT.

↳ ALL MAY LEARN AS MURIEL AND I DID WITH OUR GRANDDAUGHTER,
VICKY, THE CHALLENGE THAT MENTAL RETARDATION CAN BE TO A
FAMILY'S STRENGTH AND STEADFASTNESS -- HOW LONELY THE EXPERIENCE
CAN BE IN THE FACE OF PROFESSIONAL AND PUBLIC IGNORANCE AND
APATHY -- AND HOW PRECIOUS A PERSONALLY ACCEPTED RETARDED
CHILD CAN BE IN THE FAMILY CIRCLE.

↳ SO I AM PLEASED THAT THE PRESIDENT'S COMMITTEE ON MENTAL
RETARDATION HAS CONTINUED ITS ^{Vital} ~~VITAL~~ ROLE, WITH THE BACKING
OF THE PRESIDENT AND MEMBERS OF HIS ADMINISTRATION.

↳ I HAVE BEEN PLEASED, TOO, BY SOME OF THE RECENT GOVERNMENT
INITIATIVES THAT CANNOT HELP BUT BENEFIT THE RETARDED, ALONG
WITH ALL HANDICAPPED PEOPLE.

↳ I ALSO COMMEND THE ADMINISTRATION FOR GETTING BEHIND THE
DEVELOPMENTAL DISABILITIES PROGRAM THAT CONGRESS ~~WAS~~ ^{authorized} AND FOR
~~ENCOURAGING~~ ^{encouraging} THE VARIOUS HEW AND LABOR DEPARTMENT PROGRAMS
IN REHABILITATION AND EMPLOYMENT OF THE HANDICAPPED.

↳ FINALLY, ~~BUT NOT LEAST IMPORTANTLY~~, I CONGRATULATE THE
PRESENT MEMBERSHIP OF PCMR AND EXECUTIVE DIRECTOR JOE DOUGLASS
ON THE IMAGINATIVE "NEW THRUST" PROGRAM. ↳ THIS IS AN
ATTEMPT TO BRING TOGETHER IN A UNIFIED INITIATIVE MANY OF
THE ENDEAVORS OF CONCERN AND EFFORT THAT THOSE INVOLVED WITH
THE MENTAL RETARDATION PROBLEM HAVE BEEN PURSUING SEPARATELY.

ALL OF THESE PROGRAMS MUST CONTINUE WITH STEADY, VISIBLE,
PERSISTENT, OFTEN-REPEATED AND ACTION PROMOTING SUPPORT FROM
THE TOP, FROM THE PRESIDENT OF THE UNITED STATES, THAT IS THE
ONLY WAY THAT THE MOMENTUM OF THE ATTACK ON MENTAL RETARDATION,
BUILT UP THROUGH FOUR NATIONAL ADMINISTRATIONS, CAN BE
MAINTAINED.

IT IS THE ONLY WAY TO ASSURE THAT THE WIDE SPECTRUM OF
FEDERAL AGENCIES, WITH CAPABILITY AND AUTHORITY TO HELP THE
RETARDED AND DIMINISH THE INCIDENCE OF MENTAL RETARDATION, WILL
INDEED DO SOMETHING AND WILL WORK TOGETHER IN THE EFFORT.

ALL OF THIS IS VITAL, BECAUSE THE FIGHT AGAINST
RETARDATION WILL NOT BE WON IN WASHINGTON. WASHINGTON CAN
AND MUST TAKE THE LEAD TO HELP MAKE VICTORY POSSIBLE. BUT,
THE DAY-TO-DAY FIGHT WILL BE WAGED AND WON AS ALWAYS ON THE
LOCAL FRONT -- IN THE GREAT "OUT THERE" WHICH ALL OF US IN
GOVERNMENT TRY TO SERVE.

IT WILL BE WON WHERE TEACHERS TEACH RETARDED CHILDREN --
WHERE RESEARCHERS STUDY THE ORGANIC CAUSES OF MENTAL
RETARDATION -- WHERE PARENT ASSOCIATIONS TOIL TO BUILD
COMMUNITY AWARENESS AND ACTIVITIES -- WHERE REGIONAL CENTER
STAFFS COUNSEL THE RETARDED AND ORGANIZE PROGRAMS TO SERVE
THEM -- WHERE COMMUNITY ACTION WORKERS STRIVE TO OVERCOME
THE CONDITIONS OF DEPRIVATIONS THAT CREATE SO MUCH OF THE
MENTAL RETARDATION THAT EXISTS IN URBAN AND RURAL AMERICA.

↳ THESE ARE THE FRONT LINES OF THE FIGHT AGAINST MENTAL
RETARDATION, AND ONE OF THE CONTINUING CHALLENGES OF YOUR
COMMITTEE -- AND ALL THOSE WHO CARE ABOUT THE RETARDED -- IS
TO ASSURE THAT THE LOGISTICS EFFORT WORKS WELL AND SMOOTHLY.
IT MUST ASSURE THAT CURRENT KNOWLEDGE REACHES THE PUBLIC AND
THOSE WHO CAN PUT IT TO USE.

↳ STAFFORD WARREN, PRESIDENT KENNEDY'S ASSISTANT FOR
MENTAL RETARDATION, MAINTAINED THAT THE TOLL OF MENTAL
RETARDATION COULD BE REDUCED BY FULLY ONE HALF IF ALL WE KNOW
TODAY COULD BE APPLIED SUCCESSFULLY EVERYWHERE.

IT IS, OF COURSE, ESSENTIAL TO PLAN, TO STUDY, TO REVIEW,
TO ANALYZE PROBLEMS AND PROGRAMS FOR THE RETARDED. BUT THIS
IS FOR NAUGHT, IN MY JUDGMENT, IF ALL OF THIS ACTIVITY DOES
NOT AFFECT THE LIVES OF THE MENTALLY RETARDED AND THEIR
FAMILIES IN A POSITIVE WAY.

~~IN THIS COUNTRY~~ WE HAVE BECOME EXPERT ON STUDYING,
ON PLANNING, BUT TOO OFTEN WE DEMONSTRATE LITTLE SKILL AND
ACTION ON IMPLEMENTATION.

I KNOW THAT EVERY STATE HAS BEEN ENCOURAGED TO DEVELOP
A PLAN FOR THE MENTALLY RETARDED. AND THESE HAVE BEEN REVISED
AND UPGRADED FROM TIME TO TIME WITH NEW TYPES OF PLANS.

AT THE SAME TIME WE HAVE HAD PLANNING IN REHABILITATION,
PLANNING IN WELFARE, PLANNING IN HEALTH, BUT ALL TOO FREQUENTLY
THERE HAS BEEN NO COORDINATION BETWEEN THE PLANS AND ^{all too} LITTLE
THOUGHT GIVEN TO REAL IMPLEMENTATION.

THE DEVELOPMENTAL DISABILITIES SERVICES ACT HOLDS GREAT
HOPE FOR PULLING MANY GROUPS TOGETHER IN COMMON EFFORT. IT IS
A REAL MILESTONE IN LEGISLATION FOR ALL THE HANDICAPPED, BUT
THIS, TOO, CALLS FOR A PLAN.

↳ AND NOW THE STATES WILL BE SPENDING SO MANY HOURS COMING UP
WITH MASSIVE PAPER WORK ON PLANNING THAT I AM CONCERNED ABOUT
THE TIME AND ENERGY THEY WILL HAVE LEFT. WILL THERE BE TIME
LEFT TO IMPLEMENT BOLD, NEW INNOVATIVE APPROACHES FOR THE CARE,
TRAINING AND REHABILITATION OF THE MENTALLY RETARDED?

THERE ARE SOME OTHER CONCERNS I WOULD LIKE TO BRING TO YOUR ATTENTION, TOO.

↳ WE TALK A LOT ABOUT DECENTRALIZING OUR RESIDENTIAL FACILITIES. ↳ UNTIL WE HAVE SIZEABLE DEMONSTRATION FUNDS TO ENCOURAGE THE STATES TO PUT THIS INTO ACTION, I AM AFRAID THAT NOT MUCH PROGRESS WILL BE MADE. •

↳ WE NEED TO CHANGE THE STANDARDS FOR BUILDINGS IN THIS COUNTRY. ↳ FOR EXAMPLE, IF WE WANT TO CONSTRUCT A SMALL COMMUNITY-TYPE RESIDENTIAL BUILDING, WE STILL HAVE TO MEET OLD HOSPITAL STANDARDS BASED ON THE TYPE OF CONSTRUCTION DONE 40 TO 50 YEARS AGO. ↳ THE FEDERAL GOVERNMENT SHOULD LEAD THE WAY IN REMEDYING THIS SITUATION.

NEW TYPES OF RESIDENTIAL FACILITIES COULD COME UNDER HOUSING STANDARDS AS SET BY HUD RATHER THAN THE HOSPITAL

STANDARDS SET BY THE DEPARTMENT OF HEALTH, EDUCATION, AND

WELFARE. IF WE WANT TO GET THE RETARDED INTO THE MAINSTREAM

OF AMERICAN LIFE, THEY SHOULD LIVE IN HOME-LIKE STRUCTURES.

WE SHOULD MOVE MORE QUICKLY INTO THE FIELD OF

ACCOUNTABILITY AND EVALUATION OF PROGRAMS I BELIEVE THE

DAY HAS PASSED WHEN WE CAN CONTINUALLY FUND THE SAME PROGRAM

YEAR AFTER YEAR. THERE SHOULD BE A WAY TO DETERMINE WHAT

IS WORKING AND WHAT IS NOT WORKING -- AND THERE SHOULD BE AN

ON-GOING EVALUATION. PERHAPS THE FEDERAL GOVERNMENT COULD

INITIATE BONUS GRANTS TO THOSE STATES AND LOCALITIES THAT DO

ON-GOING, HARD-NOSE EVALUATION.

WE NEED A CONCENTRATED PREVENTION RESEARCH PROGRAM THAT
WILL BE PINPOINTED BY THE FEDERAL GOVERNMENT. IT IS TRUE

THAT THERE IS ISOLATED RESEARCH IN SOME OF THE INSTITUTIONS,

BUT, WE NEED A NEW FOCUS PROGRAM CONCENTRATED WITH ONE GOAL

IN MIND -- PREVENTION. SPECIAL EMPHASIS SHOULD BE GIVEN TO THE

BIO-MEDICAL, BEHAVIORAL AND DEPRIVATION AREAS.

WE NEED TO DEVELOP AN "ADVOCATE CONCEPT" IN THE COUNTRY.

THIS WOULD TAKE IN LEGAL SERVICES AND GUARDIANSHIP. THIS

IS PARTICULARLY NEEDED FOR THOSE LIVING IN RESIDENTIAL FACILITIES

WITHOUT PARENTS.

SEVERAL YEARS AGO THE PRESIDENT'S COMMITTEE RECOMMENDED
THE ESTABLISHMENT OF A NATIONAL INFORMATION CENTER. THERE HAVE
BEEN REPORTS MADE ON THIS PROPOSAL, BUT THERE HAS BEEN NO
REAL ACTION. A NATIONAL INFORMATION CENTER WOULD MAKE AVAILABLE
VITAL RETARDATION INFORMATION NOT ONLY TO RESEARCHERS, BUT ALSO
TO OTHER PROFESSIONALS AND TO CONSUMERS.
WE NEED MORE DISCUSSION AND SOUL-SEARCHING SEMINARS ON
SUCH ISSUES AS ABORTION AND BIRTH CONTROL. STATES ARE NOW
GRASPING WITH THESE EMOTIONAL ISSUES. BUT IS UPON US NOW
WITH BREAKTHROUGHS IN MEDICAL SCIENCE ON MONITORING THE
FETUS AND PREDICTING THE LIKELIHOOD OF A MOTHER BEARING A
HANDICAPPED CHILD.

↳ WE NEED NOT ONLY COORDINATION, BUT MANY PROGRAMS PULLED TOGETHER IN THE DEPARTMENT OF HEW THAT DEAL WITH PROBLEMS OF THE RETARDED AND THE DEVELOPMENTAL DISABLED. VERY LITTLE HAS BEEN DONE ABOUT COMING UP WITH AN EFFECTIVE DELIVERY SYSTEM ON THE FEDERAL LEVEL. ↳ ONCE WE HAVE A MODEL DELIVERY SYSTEM, THEN THE STATES COULD TAILOR THEIR STRUCTURE IN A SIMILAR MANNER.

↳ WE NEED A STRONG RECRUITMENT PROGRAM TO ENCOURAGE YOUNG PEOPLE TO WORK WITH THE HANDICAPPED. ↳ WE HAVE SCHOLARSHIPS AVAILABLE IN SOME AREAS, BUT MOSTLY ON THE GRADUATE LEVEL.

↳ WE NEED TO DIRECT OUR EFFORTS, ESPECIALLY TO THOSE YOUNG PEOPLE WHO COME FROM FAMILIES THAT CANNOT AFFORD TO SEND THEM TO COLLEGE. THIS COULD BE DONE THROUGH VIGOROUS SUMMER PROGRAMS IN FACILITIES FOR THE HANDICAPPED, WHERE THEY WORK PART-TIME AND EARN SOME MONEY. ↳ THE PART-TIME WORK COULD ACTUALLY BE ON A YEAR-AROUND BASIS THROUGH UTILIZING THESE YOUNG PEOPLE ON WEEKENDS AND IN EVENING WORK, SUCH AS COMMUNITY CENTERS.

↳ THEN THOSE WITH THE GREATEST ABILITY COULD BE GIVEN SCHOLARSHIP AID.

↳ WE NEED TO GIVE ATTENTION TO FACILITIES FOR THE RETARDED JUVENILE OFFENDER AND THE DISTURBED RETARDED CHILD. PERHAPS SOME COMMUNITY BASED DEMONSTRATION PROJECTS WOULD PROVIDE US WITH SOME OF THE NEEDED ANSWERS.

I KNOW THAT ALL OF YOU COULD MAKE IMPRESSIVE ADDITIONS TO
THIS LIST.

BUT I HAVE ONE MORE SUGGESTION. I WOULD HOPE THAT THE
COMMITTEE WOULD CONTINUE THE EFFORT THAT HAS BEEN MADE TODAY
TO KEEP FORMER MEMBERS FULLY INFORMED, SO THAT THEY CAN CONTINUE
TO ASSIST IN INFORMAL WAYS WITH THE SIZEABLE TASKS THAT REMAIN,

{ THEY ARE A VALUABLE RESOURCE, DO NOT OVERLOOK THEM.

AND TO YOU WHO HAVE SERVED PREVIOUSLY ON THE COMMITTEE,

I URGE YOU TO KEEP ABREAST OF THE WORK OF PCMR FOLLOW ITS
WORK IN YOUR AREA OF SPECIAL CONCERN. PROD THEM ON IF THEY
ARE NOT MOVING FAST ENOUGH OR HAVING THE IMPACT THAT YOU
BELIEVE THEY SHOULD HAVE.

I STAND READY AND WILLING TO HELP AND ASSURE YOU OF MY
SUPPORT AND DEVOTION.

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