



**President's Committee on Mental Retardation /
President's Committee for People with
Intellectual Disabilities**

Reports to the President

1967 – 2004

January 2010

Table of Contents

- 1967 MR 67: A First Report to the President on the Nation's Progress and Remaining Great Needs in the Campaign to Combat Mental Retardation.
- 1968 MR 68: The Edge of Change
- 1969 MR 69: Toward Progress - The Story of a Decade
- 1971 MR71: Entering the Era of Human Ecology
- 1972 MR 72: Islands of Excellence
- 1973 MR 73: The Goal is Freedom
- 1974 MR 74 : A Friend in Washington
- 1975 A Century of Decision
- 1976 Mental Retardation: Past and Present
- 1978 Mental Retardation.: The Leading Edge – Service Programs that Work
- 1979 Mental Retardation: Prevention Strategies that Work
- 1983 The Mentally Retarded Worker -- An Economic Discovery
- 1985 Mental Retardation: Plans for the Future
- 1986 Citizens with Mental Retardation: Equality Under the Law
- 1987 The President's Committee on Mental Retardation / 1987
- 1989 Citizens with Mental Retardation & Community Integration
- 1991 Citizens with Mental Retardation & The Criminal Justice System
- 1993 The National Effort to Prevent Mental Retardation and Related Developmental Disabilities
- 1994 The Natl. Reform Agenda & Citizens with Mental Retardation: A Journey of Renewal for All Americans
- 1995 Collaborating for Inclusion
- 1996 Voices and Visions: Building Leadership for the 21st Century
- 1998 A Better Place: The Contributions of Americans With Mental Retardation to Our Nation's Workforce
- 1999 The Forgotten Generation

2004 A Charge We Have to Keep...A Road Map to Personal and Economic Freedom for
Persons with Intellectual Disabilities in the 21st Century

1967

MR 67: A First Report to the President on the Nation's Progress and Remaining Great Needs in the Campaign to Combat Mental Retardation

MR. PRESIDENT:

THIS is a report about six million special Americans for whom-and for whose families -our national accomplishment has been great ... and far too little.

THE six million are the nation's mentally retarded. They are as many as the combined populations of Maine, Oregon, Mississippi, North Dakota, and Wyoming. They are as many people as live in Los Angeles and Chicago together. Their number would make 12 Indianapolises, 24 Wichitas, 48 Winston-Salems.

THESE special Americans are people who are limited in what they can do and understand and achieve.

THEY are slower to learn than most. They have greater difficulty in coping with swift change and life's growing complexity.

BUT they are not helpless or hopeless.

LIFE for them has taken on new promise since Congress, responding to popular and professional call, passed major legislation in their behalf not quite four years ago. Over \$400 million a year is now appropriated for federal programs benefiting the retarded. More than twice that amount is spent each year by the states, localities, and private citizen organizations. The result has been an extraordinary growth in the services which the mentally retarded and their families may call upon.

THE ACHIEVEMENT, HOWEVER, IS ONLY A BEGINNING

AMONG the major needs still facing us are:

- ◆ Half of the nation's 25,000 school districts offer no classes for pupils having special learning problems and needs. Many of the existing special education classes do not offer retarded students opportunity to learn and achieve to their full capacity.
- ◆ Three-quarters of the nation's 201,000 institutionalized mentally retarded live in buildings 50 years old or more-many of them "hand-me-down" mental or tuberculosis hospitals or abandoned military installations.
- ◆ The 81,000 full-time staff in public facilities for the mentally retarded must be almost doubled to reach minimum adequacy.
- ◆ The mentally retarded in disadvantaged neighborhoods often receive significantly less service from public and private agencies than do the retarded living in other neighborhoods.

- ◆ An estimated 2 million retarded persons capable of learning to support themselves need job training and placement services. Even at minimum wage, these individuals have a potential annual earning capacity of \$6 billion.
- ◆ The cause of three in every four cases of mental retardation remains unknown.

Recommendations to the President

1. Mental Retardation Services Must Be Available To More Of The Nation's People

- ◆ Particularly, ways must be found to bring these to low income, disadvantaged neighborhoods, both urban and rural.
- ◆ Community public and private agencies working with the mentally retarded must move swiftly to assure that the retarded in lower income neighborhoods receive the same services as the retarded in other neighborhoods. Provision for the needs of the retarded must be included in the comprehensive "one-stop" community health care programs now being developed. In need of special attention are medical and social measures--such as parent and child health, family planning, and counseling programs--that give promise of reducing mental retardation in "high risk" areas now having an above average rate of incidence.
- ◆ The nation's schools must plan both to improve their special classes for the mentally retarded and--because it can now be clearly shown that many children become retarded during their school years to raise their over-all instructional quality, especially in those schools whose students live in a retardation-fostering environment. Pre-school programs--such as Project Head Start--need increased emphasis in this connection.
- ◆ Private citizen organizations have especially meaningful challenges in these areas. That they have had success in stimulating and building public awareness and services in the field of mental retardation should not blind them to how much remains to be done.
- ◆ The voluntary agencies are able to express the will and apply the strength of citizens banded together for cooperative action. They should, therefore, take the lead in developing new directions for social services, effective liaison among themselves for comprehensive action, and careful, objective analyses of need and resource to assist state and national legislators in writing pertinent, effective legislation for the mentally retarded.

2. More Effective And Extensive Manpower Recruitment And Training Programs For Work With The Mentally Retarded Are Needed

- ◆ Acute shortages of professional specialists--especially teachers, therapists, physicians, social workers and nurses---continue to hamstring programs for the retarded in all parts of the nation.

- ◆ Careers in work with the retarded must be brought to the attention of the nation's young people. And the incentives-financial, career developmental, intellectual and prestigious-that would stimulate youth interest and commitment in such careers need intensive build-up.

In addition, we must open up new career fields in mental retardation programs.

- ◆ Trained, professionally recognized supportive workers can take on much of the work now done by physicians, nurses, social workers, psychologists, therapists and administrators. Here, in fact, is the most significant challenge and opportunity in the mental retardation manpower area. In such work, non-college and junior college graduates can meet great need and build satisfying careers.
- ◆ Broader use of supportive workers in mental retardation programs could also tap major reservoirs of precious human resource that are presently little utilized. For example, students (through such activities as the Student Work Experience and Training program) and elderly persons (through such activities as the Foster Grandparent Program) have created valued places for themselves in work with the retarded. Programs of this kind need major expansion.
- ◆ If, however, these opportunities are to be seized fully and the field's specialists freed to use their skills to maximum effect, many walls and barriers erected in the name of "professionalism" must be torn down.
- ◆ Finally, the priceless extras of care and help that community volunteers, both adult and youth, can bring to the mentally retarded in community as well as institutional programs need to be more widely appreciated and called into service.

3. Fuller Use Of Existing Resources Is A Necessity

- ◆ The final aim of all programs and services for the mentally retarded is that the retarded individual receive the help he needs at the time and place he needs it. All mental retardation program planners and service-giving staffs, at whatever level, should build and coordinate their efforts to contribute to the efficient realization of that aim. Appropriate incentives-- decision-making authority, opportunity to make and test innovations, and recognition of creative program contributions-should be given to encourage those planning and conducting services to participate in their steady improvement.
- ◆ The critical point for coordination of planning and service is the level at which services are given-the community.
- ◆ Agency and private organization workers with the retarded must learn how to make skillful, imaginative and full use of the many resources already available to them in their daily community contacts and from state, regional and national sources.
- ◆ They must also learn to work and think together so that each service they plan and make available for the mentally retarded and their families will join all possible and needed resources in accomplishing its purpose.
- ◆ Information and citizen involvement are -indispensable to success in this area. Governors' advisory groups on mental retardation services and state coordinating bodies should actively promote the formation of voluntary associations on behalf of the retarded in every

community (or group of communities) in their states. Each citizen should have access to a directory of state services for the retarded. Particular attention must be given to measures by which the new parents of a retarded child may receive immediate assurance that they are not alone and that there is hope and help for their child and themselves.

- ◆ Finally, families having mentally retarded children should be informed of and encouraged to make use of the casework, foster care, protection and medical services available through public and private welfare agencies.
- ◆ Work at the service-giving local level, however, must be backed by effective coordination, cooperation, and leadership at state, regional and national levels. Great improvement could be effected in these areas.

4. More Public-Private Partnerships In Program Development, Services And Research Are Needed

- ◆ Such partnerships join citizen initiative and imagination with state and federal resources. They give all levels a stake in the solving of social service problems.
- ◆ Among possible partnerships in the field of mental retardation: foundation-assisted demonstration projects in disadvantaged areas... cooperative labor-industry studies and experimental projects in employment and vocational rehabilitation of the mentally retarded... application of industry-developed systems management techniques to the meeting of local and state mental retardation needs... cooperative programs for improvement of public library resources in mental retardation materials... public grant assistance to voluntary organizations wishing to stimulate innovative services to the mentally retarded... a cooperative project of government, universities, and technical publishers to translate and make foreign-language mental retardation research and program reports available.
- ◆ Local and state governments, especially, should promote and enter such partnerships as part of an enlightened public policy to foster long-range growth that is shaped, led and endorsed by the citizens concerned.

5. A National Mental Retardation Information And Resource Center Should Be Developed

- ◆ The center would serve as a central storage and dissemination point for information on mental retardation and mental retardation programs. It would gather, systematize and furnish information on research, studies, programs and services throughout the nation and in other countries, employing the most up-to-date facilities and techniques for information gathering, storage, evaluation, retrieval, exchange and dissemination.
- ◆ Consultative services, too, would be made available through the center to mental retardation program planners and leaders at all levels, and to state and community planners of comprehensive health and social services. Also available through this center should be a basic directory that will enable any citizen to locate a contact in his state for mental retardation program and information assistance.
- ◆ To develop broad national participation, the center might be a public-private partnership, with the federal government, state governments, and private organizations in the mental retardation field assisting in its financing and costs.

6. Basic Research, Training In Application of Research, And Rapid Translation of Research Results Into Service Program Uses Need Continuing Encouragement

- ◆ Far too little, even now, is known about mental retardation, its causes, and ways to combat and prevent it.
- ◆ Biomedical research has been able to identify 25 of every 100 cases of mental retardation as associated with faulty genetic constitution or resulting from virus infections, accidents and diseases before birth or in early infancy. The body processes bringing about mental retardation in the other 75 percent of cases are still unknown, although nutritional, intellectual and cultural-environmental factors are often clearly at work.
- ◆ Knowledge resulting from scientific research now makes it possible to prevent a tantalizing one to two percent of mental retardation through tests and treatment beginning at or shortly after birth (phenylketonuria and some other conditions in which metabolic disorder can produce retardation) and through immunization (measles).
- ◆ It is imperative that many more scientists engage in studies in areas (such as biochemistry, physiology, learning) related to or bearing on the field of mental retardation, and that these scientists multiply their own efforts through greatly expanded training activities for scientific researchers and supporting research personnel.
- ◆ Better and wider use of modern technology (such as automation) will make possible the development of new or more widely applicable techniques for retardation study, treatment, and prevention. For example, automated procedures would enable the genetic study of larger numbers of people and the detection of subtle differences between normal individuals and those whose genetic make-up is such that they are "carriers" of genes associated with retardation. Progress in this area will in turn make genetic counseling more accurate.
- ◆ A special effort should be made in the study of prenatal life from its cytogenetic and physiological aspects, utilizing all appropriate clinical experience as well as the resource

afforded through the National Institutes of Health's primate research centers. Increased knowledge in this area will make prenatal diagnosis and, ultimately, prenatal therapy possible.

- ◆ Research on factors leading to a higher incidence of mental retardation in low income areas must be expanded and special methods developed for reaching such "high risk" groups through intensive family counseling and planning services.
- ◆ We also believe it a matter of national urgency that all known successful research findings and program experience applicable in the detection, treatment, and prevention of mental retardation be put to work as widely as possible. Much that is already known is not applied, or is too little utilized.
- ◆ At the same time, we must end the isolation of the United States from the world field of mental retardation study and action. Our experience and know-how are desperately needed in many parts of the world. Equally great is our need to learn from nations that have built programs for the retarded that are in advance of our own.
- ◆ Ways of facilitating information and experience exchange among U.S. and foreign researchers and programmers in mental retardation need to be developed. Early exploration should be made, for example, of an international mental retardation information and experience exchange via the scientific, medical, and educational communications satellite channels now on the drawing board. Finally, the federal government, as part of the national commitment to combat mental retardation, should help support basic retardation research and program experimentation in other countries and aid U.S. planners and programmers to study foreign mental retardation programs and problems.

7. Immediate, Major Attention Should Be Given To Early Identification And Treatment of The Mentally Retarded

- ◆ The majority of children identified as mentally retarded are not discovered until they reach school age.
- ◆ By that time, as many as three or four years-and precisely the years during which the child learns most rapidly-have been lost during which special programs could have been preparing the child to live usefully with his handicap.
- ◆ Screening of infants and pre-school-aged children for symptoms of mental retardation (as well as other handicaps) should be part of every community's public health services. School districts should offer special pre-school classes whose purpose is to begin, with the identified retarded child under five years old, the careful course of education and training that will produce a socially competent and economically productive adult.
- ◆ Instruction in the causes, treatment and social implications of mental retardation should be a part of the curriculum in all schools preparing students for careers in the health or social service fields.
- ◆ The important role that the clergy often has in family counseling should also be considered in this connection.

- ◆ In addition, all schools readying students in the health, social service, community organization and related fields must move to make their instruction and training in the techniques of individual, family and group counseling the best possible. They should, indeed, assign as much importance to this area as to their professional subject matter areas.
- ◆ All medical and social service agencies and facilities should give increased, major attention to measures that will reduce the impact of mental retardation on the family and the community. Such measures include well-baby care programs, early psychological screening and biological evaluation of children, close and continuing observation of the identified retarded child's growth, development and learning , comprehensive, coordinated medical and social services for the retarded, counseling and planning aids for the parents of a retarded child. Need for such measures as these was stirringly described in your Spring 1967 Message to Congress on Children and Youth.

8. Social And Institutional Planning For The Coming Decades Must Take Into Account The Special Needs Of The Mentally Retarded

- ◆ It is estimated that some 2,100 children who are or will become mentally retarded will be born every week in 1968.

Until more ways are found to prevent mental retardation, we must expect that up to three percent of our annual baby population will be or will become mentally retarded.

Facilities and programs for the retarded, therefore, should be considered in the compilation of every state and community development, education and social service plan, as well as in such guidelines as may be developed for federally aided urban development, housing, and comprehensive health, rehabilitation, welfare and education programs. Specialists in mental retardation should be involved in the basic social service planning process.

- ◆ Simultaneously, renewed attention must be given to public facilities and programs for the five percent of the mentally retarded who require full- or part-time residential care.
- ◆ These have not kept pace with progress in community activities on behalf of the retarded. Some of the best residential programs represent triumphs of resourceful staffs over cheerless facilities, penny-pinching budgets and general indifference. Many are plainly a disgrace to the nation and to the states that operate them.
- ◆ The states must meet their responsibility to plan, construct and maintain modern residential facilities for those mentally retarded needing them. They should retain architects to design facilities that will be cheerful to live in as well as promote maximum effective use of staff and other resources, provide sufficient funds to staff and operate the facilities at adequate levels, and integrate the facilities' operation into the over-all state plan for health and welfare services.

9. The Legal Status Of The Mentally Retarded Individual Must Be Clarified And His Rights Guaranteed

- ◆ Studies indicate that no state adequately reflects in its laws what we know of the mentally retarded today. Outmoded classifications 50 or more years old are in common legal use.

- ◆ The laws applicable to the retarded in most states deny them even the elementary rights of citizenship.
- ◆ This situation can and must be remedied through forthright action to recognize in state guardianship laws, mandatory education laws, institutionalization procedures and (for retarded offenders) penal regulations, inheritance laws, court and police procedures, and civil rights statutes that the mentally retarded are variously limited individuals whose basic human rights are inalienable.
- ◆ We particularly commend this question to the action of the legal profession through its national and state associations.

10. Lastly, We Urge That Everyone Interested In Helping The Mentally Retarded And Combating Retardation Give Thought To Imaginative Ideas And Approaches That Will Make Advances Possible

- ◆ New ideas and approaches are the catalysts that change problems into possibilities. They are needed in every phase of the nation's effort against mental retardation. Among the questions on which bold, original thinking and ideas are needed are the following:
 - ◆ What is the cost to the nation of mental retardation? That cost is known to be staggering in terms of service expenditure and undeveloped human resource. Its more precise determination and elaboration in terms of long-term national societal trends is a major planning need.
 - ◆ With jobs being increasingly designed for people, what kinds of job engineering can and needs to be done for the retarded? What kind of teaching-training techniques need to be designed for use with the retarded to ready them for jobs designed for their particular skills?
 - ◆ In the increasingly complex city, how shall we at once utilize and protect those mentally retarded who can support themselves in a job but need a form of guardianship in their off-duty hours?
 - How shall we plan to serve the mentally retarded among the 10 percent of the U.S. population who will continue to live in small towns and rural areas?
 - What will shorter work weeks and more leisure time for Americans generally mean for the retarded? Will there be adequate volunteer help available? What of recreation for the retarded themselves-what are its undiscovered potentials for bringing the retarded a greater share in the fullness of daily life? How shall we inspire young America to enter this critically important field, both as volunteers and as career workers?
 - ◆ What job, personnel and career changes and innovations will be necessary to match available skills and resources to the meeting of ever-growing need in the mental retardation field?
 - ◆ What are the moral and ethical implications of technological findings in the genetics and management of mental retardation? Should a discourse on these subjects be instituted among scientists, philosophers, theologians, social theorists, parents?

1968

MR68: The Edge of Change

Recommendations to the President

Residential Care for the Retarded

1. We recommend, therefore, that the appropriate professional and voluntary organizations, with support from the federal government, take immediate steps to improve the standards for residential care of the retarded and simultaneously develop a system of accreditation of residential care programs and facilities for the retarded.
2. We recommend that this program now be expanded to effect major change by:
 - A. Greatly increasing funds, with the provision that every state institution for the retarded have opportunity to participate.
 - B. Making awards on the basis of a state plan for bringing present institutions up to acceptable standards and the development of community based residences as alternatives to institutions.
 - C. Relating awards to the size, budget, and needs of the institution.
Particular effort in this connection must be made to meet the unmet needs of the severely and profound retarded. Accommodations and care for them are inhuman in many institutions.
3. We recommend, therefore, that a new part be added to Public Law 88-164 to establish a construction program for relocating and rebuilding obsolete residential facilities.
4. Hospital In-Service Training Program grants should be greatly increased to include significant training for both leadership and direct service personnel in residential care facilities.
5. We recommend that federal, state and local welfare agencies, both public and private, clearly identify a portion of their resources for welfare services to the retarded and their families.

Immediate strengthening of child welfare services to the retarded through expert staffing, consultation and training is an essential component of this recommendation.

6. We recommend that a federally supported insurance system be established to enable a free choice in selecting residential services.
7. In order to provide a viable choice, we further recommend that a system of loans or grants be developed to assist private non-profit and proprietary organizations to establish alternative forms of residential care for the retarded, such as hostels, group homes, nurseries, residential vocational training centers, nursing homes and extended care facilities.
8. State and local mental health authorities and the National Institute of Mental Health should take active leadership in developing services and programs for emotionally disturbed retarded persons in residential care or community programs.

Manpower to Serve the Retarded

1. We recommend that increased effort be made to attract scientists and professional specialists in education, the medical and behavioral sciences and related fields into research and service in the field of mental retardation. U. S. Department of Health, Education, and Welfare grants, scholarships and awards should be greatly expanded in support of this effort.
2. We recommend that existing grant programs such as the New Careers and Neighborhood Youth Corps programs be expanded and new grant programs be made available through the Departments of Labor and Health, Education, and Welfare to recruit, train and place supportive workers such as teacher aides, nurse's aides, social casework and family service aides, and attendants in mental retardation services.
3. We recommend a sustained effort on the part of all agencies (Continued) operating programs for the retarded and other handicapped to attract into work with the retarded, those qualified workers who may need only refresher training or slight retraining to return to work in service professions.
4. We recommend that professional groups recognize and extend professional acceptance to supportive personnel who work with their members.

We also recommend that professional specialists and their associations evaluate specialists' functions with a view to transferring as many of those functions as possible to trained supportive workers.

We further recommend that professional groups reassess in light of the preceding, any restrictions which they now place on the use of nonprofessional support personnel and reduce those restrictions to a minimum.

5. We recommend that a Department of Health, Education, and Welfare grant program be made available to each state to set up, expand or modify a volunteer service program available to both tax-supported and private programs for the retarded.
6. We recommend that institutions, schools, centers and other facilities offering services to the retarded develop employee education and training programs for employee self-improvement and upgrading. The Departments of Labor and Health, Education, and Welfare should collaborate in helping make such programs possible through grants and development of training models.

We also urge that supportive occupations in service to the mentally retarded be recognized as career opportunities, with adequate remuneration, on-the-job and other opportunities for learning new skills, and predictable lines of advancement and promotion for qualified aspirants.

7. We recommend that the Federal government develop and fund a program through which clinics, schools, residential care facilities and agencies could exchange specialist and supportive workers for mutual program benefit.
8. We recommend that occupations serving the handicapped be defined in the Department of Labor's *Dictionary of Occupational Titles* and that the dictionary's definitions then become standard reference for workers serving the mentally retarded.

The Retarded Victims of Poverty

1. We recommend that all service agencies, both public and private, act now to make health and education services available as the right of every American child from birth.

We recommend passage and full funding of the maternal and child health legislation which you, President Johnson, proposed in your 1968 State of the Union Address to assure prenatal care to mothers and first-year medical care to children in disadvantaged areas.

We also urge all necessary steps to assure systematic attention to the medical screening, health care and developmental education of children prior to school-entry age.

We recommend that the needed services be made available in urban and suburban areas through community and neighborhood health and education centers located for convenient access by all.

2. We recommend that county governments, school districts, public health districts, medical and other professional societies and voluntary organizations pool their resources to plan regional health, special education and social service facilities and programs that can handle the unique problems of specific rural areas through a combination of fixed-facility and mobile services.
3. We recommend, therefore, that federal assistance to state and local educational agencies for programs of education and rehabilitation serving those areas at all age levels be increased and significantly expanded.
4. We therefore urge that public and private agencies aggressively promote and develop career planning and opportunity in supportive health, educational and social services as an aid in supplying trained manpower for low income area programs, including those for the mentally retarded. Agencies' promotion of these opportunities should support adequate remuneration, on-the-job training activities and chances for advancement and promotion as part of supportive service occupation planning.

As part of this effort, we urge agencies and private industry to devise and conduct work training programs through which low income area residents can conveniently acquire the skills to work in supportive service positions.

We also urge the formation of a community living service modeled on the U.S. Agricultural Extension Service.

5. We urge the nation's voluntary and service organizations for children, youth, students and young adults to come to the aid of young people in low income areas, both urban and rural.
6. We recommend that family planning services and voluntary birth control assistance be made available through poverty area and other community agencies to help lower the alarmingly high rates of unwanted children and infant mortality in low income areas. We support your 1968 Health Message proposals on this subject.

We also recommend that the nation's schools promptly develop and offer a top quality program of instruction, beginning in the early elementary grades, in human biology and education for parenthood.

1. We recommend that responses to the needs of the mentally retarded be incorporated in model cities and other programs that seek to improve present communities and design the communities of the future.

We also recommend that labor, industry and commerce be involved on a larger scale in the development and redevelopment of our communities to assure adequate standards of living and community human services for all citizens.

8. We recommend that Congress amend P.L. 88-164, Part C, to give the Secretary of Health, Education, and Welfare authority to see that the facilities are located for best service to all of a given community's mentally retarded.

Requirements for matching funds should be made more flexible so they can be related to a community's average income or even eliminated in very deprived areas.

9. We therefore recommend intensification of research in the social and other behavioral sciences with the aim of isolating and defining the so-far unidentified social, environmental and cultural factors that cause or contribute to mental retardation.
10. We recommend that this network, the regional primate research centers, undertake major inquiries into the relationship to mental development of nutrition, infant stimulation, success-failure patterns and similar topics.

1969

MR 69: Toward Progress - The Story of a Decade

Recommendations to the President

1. **Mental retardation services must reach all people who need them. Particularly, ways must be found to bring these services to people needing them in the nation's low income, disadvantaged neighborhoods.**
 - ◆ There should be scores of such cooperative efforts joining national voluntary, civic and service organizations in action programs to help overcome child and adult-crippling handicaps in city and rural poverty areas. We call on every citizen to find out what his community service organizations are doing to help in this urgent need, to join in any effort being made, to take leadership if no effort is under way.
 - ◆ We also call on state and local government leaders and planners, community developers, architects, industrialists, builders and all others who create the community environment to build cities and towns that help foster healthy human development.
 - ◆ We call on public agencies and voluntary organizations at all levels in American life to give creative assistance to the Office of Child Development in realizing its purposes and programs.
 - ◆ In addition, we urge once again that the public agencies and private organizations seeking to build enduringly effective programs to overcome human handicaps in poverty areas commit themselves to:
 1. Maintain their priority attention to the programs for at least a generation in order to attain the goal of significantly reducing incidence of handicaps in children.
 2. Involve representatives from neighborhoods or communities served in their work and planning.
 - ◆ National organizations must help their local units do these things through targeted application of practical consultation, assignment of special staff and investment of new-program seed money.
 - ◆ We recommend that city and county governments, in cooperation with voluntary groups interested in the retarded, move to remedy such neglect.
 - ◆ We urge their development in every state as combined residences and sources of counsel and guidance in daily living problems for the adult retarded living in the community.
2. **Improved manpower recruitment and training programs for work with the mentally retarded must be developed.**

- ◆ The public and private agencies that employ supportive workers in their programs for the retarded should undertake a general upgrading of those personnel and their positions by whatever practicable means they can devise.
- ◆ In mental retardation programs operated by the states, the state itself, its legislators and officials, must move to change laws and regulations that have fastened archaic personnel practices on public programs for the handicapped and needy.
- ◆ Citizens themselves should demand and be prepared to support upgradings in status and salaries for supportive workers in private agency programs for the handicapped.
- ◆ Cooperatively, through the Departments of Labor and Health, Education, and Welfare, the federal government should furnish a counseling service through which field teams of expert community and institution service organizers help states and private organizations plan and carry out supportive staff upgrading and over-all improvements in staff deployment in programs for the retarded and other handicapped persons.
- ◆ The existing federal grant, scholarship and work training programs for specialists in work with the handicapped should be continued and expanded, with greater tuition assistance being made available for college undergraduates.
- ◆ In addition, we now need to make long-term, federally-supported utilization of experience from the immensely successful, low-cost programs through which disadvantaged youth, college students and senior citizens have been working as aides in programs for the retarded.

3. Fuller, more imaginative use of resources- including the resource which the retarded themselves represent- is needed at all levels.

- ◆ We urge, therefore, that federal funding for mental retardation research, training and demonstration-improvement programs (including university-affiliated programs) continue, with evaluation of the effectiveness and results of these activities being made within the next year.
- ◆ We also recommend that mental retardation facilities construction and staffing appropriations be maintained so that the intent of Congress in providing (in Public Law 88-164) for a national network of operating mental retardation research and training centers can be realized.
- ◆ At the same time, we urge state, county and local government planners of mental retardation services and facilities to develop their long-term program operations on the foundation of their jurisdictions' tax bases.
- ◆ Most retarded young people need training that develops skills and attitudes for daily work-and living.
- ◆ It should in any case be a realistic curriculum that readies individuals to meet the actual demands of daily living and to work in jobs that actually exist in the community.

Business, industry and labor could play a much more significant role in this effort than they presently do.

- ◆ Finally, an on-going counseling service should be available to the retarded who are on their own in the community.

4. More public-private partnerships in mental retardation program planning, services and research should be developed.

Many of the measures recommended earlier in this report and in previous reports could and should be developed through such joint action.

Among them:

- ◆ Comprehensive health and child development centers in poverty neighborhoods.
- ◆ Vocational and job education, training and employment programs for the retarded and other handicapped as well as job analysis and redesign to better fit retarded workers' skills and capabilities to work norms and needs, in both service and manufacturing industries.
- ◆ Establishment and operation of developmental training facilities for the retarded living in rural areas.
- ◆ Government-foundation partnerships formed to develop and carry out innovative, demonstration and special-need programs in the mental retardation field. Such partnerships might also absorb some of the cut when federal funding of local-based mental retardation programs is reduced before the community and its agencies are able to assume full program support.
- ◆ Development and cooperation of high quality residential care facilities that will permit parents or guardians of retarded individuals a free choice among varying program options. Such a choice is available today only to the affluent. In addition, states should enter public-private partnerships for the development and operation of community group homes for the retarded.
- ◆ Continuing operation of a national mental retardation public information and education campaign.

5. Basic research in mental retardation and rapid translation of research results into service program uses need continued encouragement.

- ◆ The basic research that has produced these historic findings continues critically needed, as does the research and experimentation that makes the outcomes of such findings conveniently, economically available to every American needing-them. We urge that human development research be included in the first rank of the nation's action priorities and that broad-based public and private support from the health, education, social service, behavior and related fields be given to such research.
- ◆ To stimulate and coordinate research into the basic human learning processes, therefore, we urge action now on the establishment of a national learning institute or foundation. This foundation would particularly promote investigations of human learning processes and

potential that join a number of disciplines. The foundation should be a public-private partnership organized and funded in much the same way as the National Science Foundation.

- ◆ We recommend, therefore, that public agencies and private organizations having programs related to human development and learning problems such as mental retardation earmark a steady portion of their budgets to the cooperative evaluation and application of new information affecting their programs.

6. The special needs of the mentally retarded should be taken into account in social and residential care planning for the coming decades.

- ◆ We must plan for the lives and careers of these retarded in tomorrow's communities, schools, working places, leisure-time programs and residential facilities.
- ◆ And we must make as great as possible integration of the retarded into normal community living and working patterns the objective of that planning.
- ◆ In the community of the future there should be no such thing as a separate population of mentally retarded people for whom there are special group programs.
- ◆ Every state that has large, mass custody programs for the retarded should move vigorously to develop quality programs that are aimed at habilitation of retarded individuals for fullest possible participation in community living and work.
- ◆ Lastly, but far from least significantly, every state should review and reform its laws that affect the status and rights of the mentally retarded.
- ◆ We also recommend that the nation's voluntary associations working for the retarded redouble their efforts to involve state legal and judicial groups in the study and revision of guardianship, commitment, minority and other laws as they affect the retarded.

1970

MR 70: The Decisive Decade

Recommendations to the President

1. Residential Services

- ◆ For the approximately 275, 000 people who live in the nation's public and private residential facilities for the mentally retarded, and the thousands more who are on waiting lists to enter those facilities, there's big news- fundamental change and improvement are on the way.

2. Malnutrition

- ◆ Malnutrition and under nutrition are major causes of impaired human mental development.
- ◆ In 1971, the President's Committee on Mental Retardation will publish a report presenting in detail what is known today through research and observation about the relationships of malnutrition, general health, mental deficiency and allied factors. In issuing the report, which is presently in final stages of preparation, the Committee will make practical recommendations of steps that private organizations and government at all levels can take to reverse this common and most needless of all causes of mental retardation- lack of adequate nutrition in our land of plenty.

3. Research

- ◆ Biomedical and behavioral research in mental retardation and allied areas pays off. Little noticed amid the multitude of multi-million-dollar searches for causes of cancer, heart disease and other major crippers, the comparatively modest is of mental retardation, human development, learning handicap and neurological researchers have been making extraordinary progress in early diagnosis, prevention and relief of retardation.

We urge, therefore:

- ◆ Continued support for biomedical and behavioral research activities and facilities;
- ◆ Continued development of programs for training medical students in research careers;
- ◆ Continued development of needed legislation in such as the Developmental Disabilities Act;
- ◆ Continued dissemination of research results to the agencies and individuals needing them;
- ◆ Continued widespread involvement of citizens in such activities as measles immunization campaigns, birth defects information efforts and volunteer assistance in the centers, classrooms and agencies where the results of research are being put to work for the people.

4. Education

- ◆ In the late summer of 1969, PCMR sponsored, with the Bureau of Education for the Handicapped of the U.S. Office of Education, a conference on the learning problems of inner city children.

Recommendation 1: Provide early childhood stimulation, education, and evaluation as part of the continuum of public education.

Recommendation 2: Conduct a study of histories of successful inner-city families who have learned to cope effectively with their environment.

Recommendation 3: Restructure education of teachers, administrators, and counselors. Retain those now in the field.

Recommendation 4: Reexamine present system of intelligence testing and classification.

Recommendation 5: Commit substantial additional funding for research and development in educational improvement for disadvantaged children and youth.

Recommendation 6: Thoroughly delineate what constitutes accountability, allocate sufficient funds to carry out the responsibility entailed and hold the school accountable for providing quality education for all children.

Recommendation 7: Involve parents, citizens and citizen groups, students, and general and special educators in total educational effort.

5. Employment

- ◆ During the past decade the mentally retarded have entered the work force in significant numbers for the first time. It has been an eye-opening experience for all concerned.
- ◆ The President's Committee on Employment of the Handicapped and PCMR have together come to the conclusion that the education and training of a mentally retarded person should be vocationally oriented from their beginning. They should be pointed toward the kinds of jobs that will actually exist in the area in coming years. And school programs of education and training for the retarded should be flexible enough to develop good work skills and attitudes in the broad range of ability levels among the retarded who can benefit from school programs. These programs should also continue up to the point at which the retarded individual moves into the job he will hold (no gap between training and work), with counseling assistance continuing as needed at least until the new worker is demonstrably adjusting well to his working conditions, co-workers, and being on his own.

6. State Services

- ◆ Progress and improvement in the lives and prospects of the nation's millions of mentally retarded individuals depend, ultimately, on how well the services they need are delivered. And how well the services are delivered depends primarily on the planning, efficiency and

effectiveness of the state and community agencies that administer and furnish public programs and services for the handicapped.

7. Additional Action Areas

- ◆ During the past year, the President's Committee on Mental Retardation has continued its long-term studies and initiative in the areas of legal rights and guardianship of the retarded, manpower planning and utilization, and international information exchange activities.

1971

MR 71: Entering the Era of Human Ecology

Recommendations to the President

Designing an educational framework based on human ecology to train people to meet biological, behavioral, educational and social needs within the human development timetable throughout the life cycle.

This approach to the understanding of the nature of man and his potential wholeness is an essential academic requirement of this nation. Therefore we recommend:

- ◆ Universities be encouraged to develop a comprehensive curriculum and academic program for a new kind of college devoted to human ecology.
- ◆ Governmental health and environmental services supply and coordinate knowledge of human ecology toward a decisive reduction in mental retardation.

Experimental, Control, and Contrast Group IQ Scores

- ◆ Developmental day care centers, including educational, health, and nutritional services, be made available to America's children, with priority to those with special needs.

Intelligence

Questions Considered (IQ Tests)

- ◆ How valid is the evaluation?
- ◆ How valid is the testing?
- ◆ How valid is the placement process?
- ◆ How valid is the use of instruments to place the children?
- ◆ What are the social implications of placement?
- ◆ What are the legal implications?

Conference on Placement of Children with Mental Retardation

(PCMR, Bureau of Education for the Handicapped, Council for Exceptional Children)

Conference Recommendations:

1. Improve and restructure the current testing, placement and evaluation process for identifying children as mentally retarded.
2. Cease labeling children as mentally retarded unless a comprehensive assessment of mental ability, physical health, and adaptive behavior demonstrate a handicap severe enough to justify the designation.
3. Advocate educational justice and freedom for all children through recognition of each child as a unique individual.

4. Sensitize teachers, administrators, school counselors and staff, curriculum developers, and teacher educators to the pervading discrimination against children from social, cultural, ethnic, and economic backgrounds different from the so-called norm.
5. Use the existing legislation, and the Courts, if necessary, to achieve educational justice.
6. Support educational reform through Federal, state and local governmental and private funding.

Genetic Damage

- ◆ That the opportunity for genetic counseling and amniocentesis for prenatal screening be provided to all high-risk mothers requesting such services.
- ◆ That research and clinical study of fetal development be increased.

Lead Poisoning Awareness

The Committee is formulating a policy statement on lead poisoning to emphasize the Committee's interest in this preventable cause of mental retardation. PCMR is also assisting in the development of pilot projects based in children's hospitals in "lead belts" to clarify the extent and clinical severity of the problem and to seek solutions.

First Pacific Forum on Mental Retardation

Delegates from 17 countries met in Honolulu, HI- Sept. 28 - Oct. 1, 1971

With the United States having trust or other governmental responsibility for several islands in the Pacific, and a continuing tradition of interest in the entire Pacific area, PCMR deemed it important to establish a more effective exchange of ideas among the nations concerned.

Priorities

1. Assistance in developing further professional and paraprofessional training programs for parents, teachers, and others;
2. Research the findings to be translated and disseminated;
3. Professional assistance in enlightening the public;
4. Development of exchange leadership programs;
5. Periodic conferences

International

The PCMR and the National Association for Retarded Children cosponsored an International Symposium on Volunteers for the International League of Societies for the Mentally Handicapped, held in Pennsylvania.

Topics included:

Training volunteers, youth volunteers, professionals, and related subjects.

Participants came from:

Belgium, Brazil, Canada, Chile, Colombia, England, France, Germany, Sweden, Switzerland and the United States.

Goals of PCMRs New Thrust

- ◆ To reduce the occurrence of mental retardation by 50 percent before the end of this century.*
- ◆ To largely eliminate Down's syndrome (Mongolism) within the next two generations.
- ◆ To avoid the disastrous effects of rubella and other viral infections, by inoculation, vaccination, and other preventive measures.
- ◆ To undo the harm done thousands of children wrongly identified as retarded by faulty tests.
- ◆ To prevent the retardation that would occur because of social neglect and public disinterest in great segments of minority groups.
- ◆ To permit conception and birth of normal, healthy infants through genetic counseling of parents-to-be and prenatal care of the mother.
- ◆ To return one-third of the retarded now living in institutions to community living, and make them into useful citizens through training for productive employment.*

*Since this report was written, President Nixon has declared these to be "major national goals."

1972

MR 72: Islands of Excellence

Recommendations to the President

1. A Mental Retardation Coordination and Liaison Office at the highest administrative level should be established in Federal departments of executive agencies that have not already done so. Through these offices, the departments and agencies should work with the President's Committee on Mental Retardation for a coordinated effort. Similar action should be taken at the regional level, involving Federal, State and local representatives.
2. A plan should be formulated by the involved Federal departments to aid State and local governments in implementing community services as alternatives to institutionalization of mentally retarded persons.
3. Public agencies and private businesses capable of helping retarded persons to find competitive or sheltered employment should reexamine and intensify their efforts to secure far more job placements. A chance to do work according to their highest potential is crucial to a better life for retarded persons.
4. As a prime means of preventing handicaps, efforts should be concentrated on improving maternal and infant care.
5. The Federal Government should make fullest use of existing Federal authority to act on behalf of legal rights of the mentally retarded, and should consider enlarging that authority.
6. Appropriate agencies and organizations should work with PCMR in focusing information and education resources to create greater public awareness of prevention possibilities and a climate of community acceptance for retarded persons.

1973

MR 73: The Goal is Freedom

The PCMR Believes.....

- ◆ Mentally retarded people are capable of continuing development.
- ◆ Corrective measures introduced in early childhood can reduce the severity of the handicap and sometimes reverse its course.
- ◆ Prenatal and neonatal biomedical intervention can prevent many forms of mental retardation and related handicaps.

MR 74: A Friend in Washington

Major Committee Activities:

- ◆ Analysis of the “state of the art” from the beginning of this century;
- ◆ Series of regional forums to hear the people concerning the trends, issues, problems and progress in the field;
- ◆ Series of reports from states, national and international organizations reflecting major governments and policy;
- ◆ Dialogue with Federal agencies and Departments;
- ◆ Assistance of “futurists” in forecasting the shape of society in the year 2000 as a basis for recommending goals related to prevention, humane services, full citizenship, and public awareness.

International Affairs

- ◆ Several planning sessions centered around the Second Pan-American Congress on Mental Retardation, to be held in Panama in August 1975.
- ◆ The first such conference was held in Puerto Rico (1964), as an outgrowth of the President's Panel on Mental Retardation.
- ◆ To plan the Congress, PCMR met with representatives of the State Dept., HEW's Office of International Affairs, The Organization of American States, Partners of the Americas, Panama and UNESCO.
- ◆ In addition, preliminary planning was done on programs for training personnel in other countries, especially in developing countries, to work with retarded persons. Included in these plans is the projection of a system of an international exchange of information on mental retardation.
- ◆ PCMR representatives participated in the International Conference on Special Education in Spain, the International League of Societies for the Handicapped Symposium on Mental Retardation in Brazil, the Caribbean Conference on Mental Retardation in Barbados, and the World Conference on Rehabilitation Medicine in Mexico City.
- ◆ Visitors from Sweden, Poland, Korea, England and countries of South and Central America met with PCMR staff and members to discuss their programs and exchange ideas.

MR 75: Mental Retardation: Century of Decision

Recommendations to the President

Full Citizenship and Legal Rights

The Attainment Of Citizenship Status, In Law And In Fact For All Mentally Retarded Individuals In The United States, Exercised To The Fullest Degree Possible Under The Conditions Of Disability.

The assurance of maximum freedom to exercise legal and constitutional rights and responsibilities.

- ◆ A duly selected body, working in concert with public and private agencies, should develop at an early date, a legislative guide and information-sharing system, to be used by the States to develop statutes to protect the constitutional rights and facilitate full citizenship of mentally retarded and other handicapped persons.
- ◆ All States that have not already done so should institute a careful review and revision of their statutes and legal practices relating to mentally retarded and other handicapped persons, to ensure conformity with constitutional guarantees of equal rights' due process and equal protection of the laws.
- ◆ A nation-wide system of "public" legal advocacy services specializing in the protection of rights should be available to mentally retarded and otherwise handicapped persons. Branches of this system should be established in all States.
- ◆ Offices of special appeal, with final recourse to the courts, should be available in each State to protect the rights of the retarded and other handicapped individuals, as well as those of others. The offices should be established as commissions or public corporations separated from the regular governmental systems, with authority to act independently on behalf of handicapped citizens.
- ◆ Statutes and court procedures bearing on competency should be clarified and revised a) to recognize gradations of competence, b) to recognize that areas of competency may be quite varied and therefore should be separable in law, c) to assure full and explicit due process safeguards on any and all areas of competency, and that the scope of any judgment of incompetence is made fully explicit, and d) to ensure that restrictions of competency be limited to a specific period of time or subject to periodic review.
- ◆ The LEAA program of the Department of Justice should concern itself with a variety of matters affecting mentally retarded persons in both the civil and criminal justice systems. These would include the clarification of procedural matters; pre-service and in-service training of lawyers and law enforcement, court, juvenile justice, and criminal justice personnel in the nature of retardation, the legal and constitutional rights of handicapped

persons, and procedures relating to retarded individuals; and the provision of funds for research and study of these matters.

- ◆ All professional persons who work with mentally retarded individuals should be trained to recognize issues of human right, including but going beyond legal issues.
- ◆ Educators, social workers, and other counselors should be trained to impart to mentally retarded persons an understanding of their rights and concomitant responsibilities in a more open society.
- ◆ Establishment of programs 1) to prevent delinquency in retarded persons at risk, 2) to divert the handling of retarded offenders from the regular criminal courts to other procedures, and 3) to provide corrective rehabilitation of retarded juvenile and adult offenders.
- ◆ Every effort should be made to consider and resolve issues in regard to maintenance of and access to records of handicapped and other persons. The issues revolve around the rights of privacy, personal access, confidentiality of communications, "need to know," and appear to involve issues of conflict of rights.

The assurance of maximum independence of retarded citizens.

- ◆ The development of a compendium handbook, subject to annual revision, codifying statutory provisions of the States and Federal Government concerning:
 - ◆ Legal status, competency adjudication, and guardianship (both of person and property) for mentally retarded persons.
 - ◆ Protective, developmental, and supportive services for mentally retarded persons.
- ◆ Development by progressive steps of a system which will guarantee fully adequate economic security and independence to all people, including mentally retarded individuals. Such a system should begin with current Federal and State programs and develop over time the following provisions:
 - ◆ A guaranteed minimum income adequate to meet the normal costs of daily living.
 - ◆ A credit or voucher system, vested in the individual retarded consumer in need, whereby retarded individuals could acquire necessary special services from a choice of accredited providers. Nothing in these recommendations exempts service-providing agencies from the application of eligibility standards or from accountability in expenditures as provided by law.
- ◆ In any modifications of economic security statutes, HEW and the States should provide by law and regulation, for the recognized privilege of any certified personal representatives, selected by, or under contract to, a mentally retarded person or his legal guardian, to serve as his agent and to negotiate for services in his behalf.
- ◆ The Federal Government should provide financial assistance to the States to cover costs of transition of individuals from institutional to community services, and costs of transforming

or replacing central institutions for more functional purposes consistent with the needs of retarded citizens.

- ◆ A public corporation or commission should be established in each State to provide guardianship services, including the certification of persons qualified to serve as personal representative agents.
- ◆ Legislation should be developed by the Congress and the States to authorize and fund adequate systems of humane services to develop, support, and protect the rights of retarded persons as citizens.

The assurance of maximum access to a free and open community.

- ◆ Institutional commitment, non-voluntary or voluntary, should be prohibited by law except through due process procedures establishing that it is required to prevent the person from doing harm to himself or others, that it is the least restrictive solution available, that the period of commitment is specifically limited and subject to court review, and that the subject is represented by counsel at commitment hearings.
- ◆ Public laws should be established and enforced requiring the use of positively assisting devices to enhance the freedom of movement and safety of the mentally and physically handicapped in all public buildings, transportation systems, public ways, and publicly financed housing.
- ◆ State laws and local ordinances should protect the right of handicapped persons to appropriate residential arrangements, free of discriminatory zoning regulations, inappropriate licensing standards and codes.

Prevention: The Right To Be Well Born

Reduction of the incidence of mental retardation from biomedical causes by at least 50 percent by the year 2000.

Full commitment of the people of the United States to the prevention of mental retardation from causes operative in reproduction and prenatal development.

- ◆ A national education effort supporting planned pregnancies, which emphasizes optimal conception and maternal health, will be the most effective means to reduce incidence of mental retardation. This effort will ensure the early use of known ways of avoiding the occurrence of mental retardation.
- ◆ Genetic diagnostic and counseling services are needed by high-risk persons. Outreach genetic services must be extended from university and medical settings to more people in need, especially those in rural settings and in vulnerable population groups.
- ◆ Couples should be encouraged to take due account of what is known about the timing of pregnancies in terms of maternal and paternal age, and to have their children during the optimal reproductive age.

- ◆ Couples should avail themselves of all knowledge that will improve the probability of bearing normal children. The discussion with one's physician of any factor in family history bearing on mental or physical problems may aid in identifying couples at risk for mental retardation. This may be followed where needed by genetic counseling or application of preventive techniques which can reduce disabilities from inherited factors and allow the birth of normal children.

A health delivery system is needed which assures equal access to quality care at reasonable cost.

- ◆ Comprehensive maternal and child health care services must be available and accessible to all women and their children, including those families with low income and those residing in rural areas.
- ◆ Exposure of pregnant women to radiant energy sources, infectious agents, dangerous drugs, and other known and suspected hazards should be minimized until research has clarified the extent of danger these influences pose for the developing fetus.
- ◆ Malnutrition, which is a contributing factor to prematurity, low birth weight, and neurological abnormalities, should be decreased by all means available, including public education on known nutritional hazards, accurate consumer information on nutritional values of processed foods, and by selective supplementary diet for high-risk pregnant and lactating women and their children.
- ◆ Routine periodic developmental assessment of all preschool children from birth should become a normal and accepted part of child-rearing practices in order to detect and treat incipient developmental problems at an early stage.
- ◆ Programs for prevention and treatment of child abuse are necessary to reduce risk of brain damage. Physical abuse of children can cause neurological damage including mental retardation. It should be noted that some children with mental retardation are at an increased risk of being abused.
- ◆ Persons with mental retardation must be served in all health care systems, both medical and dental, available to the general public.
- ◆ To reach all persons in need, a more equitable distribution of health manpower and resources must be developed. Medical, communications, and transportation technologies must be more broadly exploited.
- ◆ An interim system of cooperative funding can provide the needed preventive and ameliorative health care during the next decade. Intensive study of its operation can lead to development of subsequent funding systems during the balance of the century.
- ◆ More rigorous identification and eradication of toxic substances in the environment, such as lead paint, airborne lead, waterborne mercury compounds, and specific organic toxic compounds, should be pursued.

Continued advancement of knowledge through research.

- ◆ Advancement of basic information in reproductive biology is needed in order to understand

and to ensure normal fertilization and gestation, and to reduce incidence of genetic error.

- ◆ A broader understanding of fetal development will offer options for diagnosis and treatment in the prenatal period.
- ◆ Research is needed to improve contraceptive alternatives to reduce unwanted pregnancy and allow optimal planning of reproduction.
- ◆ New approaches and techniques are needed for improved research analysis of such complex medical/social problems as nutrition, child abuse, drug abuse, and environmental hazards, and their effect on incidence of mental retardation.
- ◆ Research methods are needed to explore child growth and development following maternal disease during gestation, obstetrical complications, prematurity, and prolonged respiratory support. Continued fetal research is needed to assess the impact of environmental agents which may have toxic effects, or produce congenital deformity or genetic mutation.
- ◆ The effects of maternal drug use and drug abuse on the fetus require research.
- ◆ Emphasis should be given to those goal-oriented research programs that address identified problems and produce the most cost-effective prevention of mental retardation, but not at the expense of broad basic research.
- ◆ A major effort is needed to bring together separate research findings systematically for more effective compilation, technical implementation and application to prevention.
- ◆ An effective information center should be established at the national level to identify and monitor current research related to prevention of mental retardation in order to improve the flow of information and its application in service delivery.
- ◆ A coalition to include private, public, and consumer groups is needed to gain broad support for biomedical, behavioral, and environmental research designed to prevent or ameliorate mental retardation.
- ◆ Public education must be developed to create understanding of the benefits to be derived from basic biomedical, behavioral, and environmental research.
- ◆ Research and demonstration programs are needed to further develop effective strategies for facilitating advancement of young developmentally delayed and mentally retarded children. Such programs must be field tested on a broad scale before being implemented on a massive basis.

A total campaign of public education on the known means of preventing mental retardation must be developed.

- ◆ School curricula at all appropriate levels should include information on the following subjects related to parenthood:

- ◆ Human reproduction; Growth and development of children; importance of the parent-child relationship in the social, emotional, and cognitive development of the child; Hazards of some modern life-styles to the birth of normal children.
- ◆ Education for health-related careers should include training in the following areas:
 - ◆ Consumer participation and social problems; Inter-disciplinary team collaboration in patient care; Administration of multi-disciplinary service programs; Preventive and public health aspects of all health specialties in relation to problems of mental retardation and developmental disability.
- ◆ Various chemicals, some medications, and excessive amounts of alcohol and nicotine during pregnancy can increase the risk of having a mentally retarded child. Women should be impressed with the importance of seeking their physician's advice before using any such products when planning pregnancy.
- ◆ The public should be informed that chemical and other environmental pollutants exert unknown but potentially hazardous effects on the developing fetus. Such awareness should provide added impetus to the necessary research and enforced controls of environmental hazards.
- ◆ Obtaining medical care early during pregnancy ensures the best opportunity to monitor both the mother's and the baby's health. The importance of such early care should be brought before the widest possible public.

Prevention: The Right to a Good Start in Life

To reduce the incidence and prevalence of mental retardation associated with social disadvantage to the lowest level possible by the end of this century.

Elimination of prejudicial attitudes and discriminatory practices based on race, ethnic membership ("racism") or social class as a root source of impaired or retarded human development.

- ◆ The President of the United States, the Congress, and the Courts must exercise continued leadership in the elimination of attitudes and practices that create disadvantage to minority persons in achieving their potential human development.
- ◆ Affirmative action in compliance with statutory requirements must be vigorously implemented to assure that minority and disadvantaged individuals will be appointed to boards, commissions, and administrative positions with decision-making responsibility on matters affecting the developmental opportunity of all persons in need.
- ◆ The selection of personnel in all departments to administer Federal and State programs designed to meet the needs of poor and minority group persons must include consideration of appropriate experience, training, and sensitivity to the special problems, attitudes and value systems reflecting ethnic and economic differences.
- ◆ Community Action Programs should be continued and funded on a national level with emphasis on greater involvement of poor and minority persons in decision-making and on the creation of a climate of self-esteem and personal worth conducive to personality growth and mental development.

Improvement of home and community environment and living experience through a persistent attack on conditions which impede or distort full development of human potential among poor and minority groups.

- ◆ The national Home Start program to assist low-income parents in the early developmental training of their children in their own homes should be developed systematically as knowledge and experience expand. This effort should use the best means available to stimulate the cognitive development of children through parent-child and other social interactions, with due respect for cultural differences.
- ◆ Continued and sustained research at basic and applied levels must be supported by appropriate Federal agencies to develop knowledge and implement the best means of early assistance to families and children at risk from psychological and social hazards.
- ◆ The total home and community environment must be improved for minority, poor, and otherwise deprived people in areas such as housing, health services, recreation, employment, and nutrition.
- ◆ The current welfare system should be revised to provide for the training and utilization of welfare service workers indigenous to the neighborhoods to which they are assigned. Based on intimate knowledge of their constituencies, such workers would provide welfare recipients a basic consumer education relating to purchase and preparation of food for adequate

nutrition, making and buying clothing, purchase of needed services, and other aspects of home and family management.

- ◆ Access to child development centers for poor and minority group children should be on an equal basis with all families in need of such service. This would be supplemental to home-centered training programs recommended above. Such centers should be strategically designed and located to serve both urban and rural communities.
- ◆ Monetary aid must be provided to low-income parents for education and employment training as a means of improving the economic and psychological life of the family.
- ◆ More direct health services to needy families should be provided on a progressively improving basis. Such services should stress preventive and ameliorative measures of all kinds relating to hazards to child development and mental functioning.

Equal educational opportunity for all persons, encouraging cultural differences without penalizing and damaging development.

- ◆ Methods and procedures must be improved for determining the educational needs of individual children exhibiting problems in school. Labeling and assigning children to classes for the mentally retarded by cursory procedures employing inappropriate tests is discriminatory and unjustified, especially when applied to children from cultures other than those on which tests have been standardized.
- ◆ In support of the previous recommendation, broad programs of educational research and development should be Federally funded over the next 25 years to discover and develop the best approaches to equitable individualized education for all children, including the development of improved, culturally sensitive assessment methods.
- ◆ Curricula for certification of teachers, administrators, and other educational personnel should include courses focusing on both the positive and negative impact of racial, ethnic, and economic factors on human development.
- ◆ Teachers working with children who are in any way disadvantaged should be specially trained and qualified and should receive commensurate salary and advancement incentives. This is designed to eliminate the still-persisting tendency in some school systems to assign inferior or incompetent teachers to work with disadvantaged, handicapped, or behaviorally different children, and to practice other forms of covert discrimination which have the effect of increasing rather than reducing disadvantage.
- ◆ Higher education institutions should develop outreach programs of continuing education and field-based programs of training associated with community service settings. A major focus of these programs should be on upgrading the quality of life of poor and minority groups, and on the prevention of environmentally related retardation.
- ◆ Minority institutions of higher education are uniquely qualified to deal with problems experienced in minority and poverty settings; therefore, Federal funding activity should take advantage of this expertise and ensure that it is utilized to the greatest possible extent. Minority colleges serving primarily the disadvantaged must receive an equitable share of

State and Federal funding. Present statutory provisions requiring equitable funding and affirmative action on personnel practices must be positively implemented.

Provide adequate controls on the allocation and use of public funds, to safeguard the interests of the populations most at risk from social and economic disadvantage.

- ◆ The Federal Government must assure, within the language of enabling legislation or by clear designation of legislative intent, how funds are to be allocated and spent in programs for poor, minority, and handicapped persons, and require demonstration of compliance.
- ◆ Legislation for health, education, and welfare programs must ensure proper monitoring and accountability of programs for people who are mentally retarded, based on outcome criteria in the lives of those served.

Humane Service Systems

Adequate and humane service systems for all retarded persons in need of them.

A comprehensive array of service resources available to meet the essential needs of all retarded persons in all sections of the United States.

- ◆ A minimum array of essential developmental, supportive, and protective services must be guaranteed to mentally retarded persons by Federal action in collaboration with the States, as a first order of priority. Services beyond such minimum levels must be developed and supported on a timely schedule.
- ◆ Services must be equitable and delivered according to need; provided through public, voluntary or purchase sources, with emphasis on access by choice; delivered by competent manpower selected for its trained capacity to meet service objectives; focused on helping retarded persons achieve the highest possible levels of personal and economic independence.
- ◆ Interdepartmental policies at Federal and State levels should emphasize coordinated, simplified, and unified procedures for application and eligibility determination, so that mentally retarded consumers can get the services they need.

The exercise of free choice and decision by every retarded person or his personal representative in matters that concern his interests.

- ◆ No major decision should be made on behalf of a mentally retarded person except by himself, or by an agent whom he or a duly constituted authority designates to speak for him; this principle must be established by law, regulation, and judicial initiative, and should be assured by HEW, the Department of Justice, and the States.
- ◆ Administrative procedures of service agencies must reflect the right of the mentally retarded person or his personal representative to select freely any service of his choice for which he is eligible and to express need and demand for those services which his disability requires. This includes the right to coordinate such services for his own unique purposes and to change service agencies at will, as other people normally do. To this end, all Federal agencies and the States should officially recognize this principle through policies, regulations, and affirmative action.

- ◆ The exercise of meaningful choice or decision requires a basis of informed participation and consent. Consequently, all Federal agencies and the States must provide suitable means of guaranteeing mutual understanding on any matter requiring choice and decision affecting a mentally retarded person.

The availability of a personal representative for every mentally retarded person who wishes or requires one.

- ◆ Public policy must assure to every mentally retarded person or his legal guardian opportunity and means to select or employ an agent or agency as his personal representative, to negotiate on his behalf for any available service he requires, no matter how brief or extended his need for service may be. Such policy should be embodied in law and regulation, and must provide for funds or credits to assure to each retarded person the means of free selection of such an agent. The agent or agency selected as a personal representative must be completely independent of any serving agency or system, except that recognition and qualifications for such representative should be established by law.
- ◆ In order to stimulate the supply of persons qualified to give competent representation as service brokers to mentally retarded clients, and to protect against exploitation by unqualified agents, HEW and the States should provide by statute and support for the recruitment, training, and certification of persons with the knowledge and skill necessary to perform this function.

Maximum opportunity for every mentally retarded person to live in a local community setting of his choosing.

- ◆ Using available legislation, the Federal Government and the States must develop long-range programs so coordinated as to assure mentally retarded persons an increasing range of choices as to where they shall live. The choices may vary from independent living to fully protected care, and should be responsive to consumer demand.
- ◆ Coordinated with residential alternatives in the local community, there must be developed appropriate, adequate services essential to help retarded persons remain in homes of their own choice, including living with their own families, with friends or by themselves.
- ◆ Restrictive building and safety codes and zoning ordinances must be modified to recognize the degrees of independence and responsibility of retarded persons living in the community.
- ◆ Central, comprehensive, publicly supported institutions for mentally retarded persons must undergo an orderly process of change from their traditional role as long-term, all-purpose, high-capacity and self-contained organizations to that of care and treatment facilities for specific purposes, with capacity governed by purpose.
- ◆ States and communities should utilize technical assistance, such as environmental consultant services, involving functional designing principles and flexible design models, for both community and central residential settings for the mentally retarded.

- ◆ Comprehensive review and continued research should be conducted on the effects of all types of residential service on the development of retarded persons with varying impairments.

Maintenance by all serving agencies of standards of quality and accountability acceptable to the community and to the individual mentally retarded persons being served.

- ◆ A basic code of uniform standards of service for mentally retarded persons should be adopted by Federal departments serving mentally retarded persons, and by the States. The code should consist of fundamental principles directed toward service outcomes, rather than specific and detailed procedures. Substantial observance of these standards must represent a condition for any public financial support for delivery of such services. Waivers should be granted only on specific justification provided by law and regulation. There must be legal, administrative and budgetary provision for enforcement of these standards, and reasonable but limited time for existing facilities to demonstrate compliance.
- ◆ A workable system for the reporting, storing, codifying, analysis, evaluation and dissemination of information on service delivery to mentally retarded persons must be designed and put into operation at the earliest possible time. The resulting information should be disseminated in summary form to the public at large, and regularly updated.
- ◆ In order to effect quality control, Federal departments serving mentally retarded persons should put into effect a financial reward and penalty system applicable to all formula and discretionary grant funds to the States. This system should be responsive to proven ability or failure to provide needed services, maintain quality standards or meet reporting obligations. The system should be based on small but significant increments or decrements in financial support for achievements of or failure to meet obligations.
- ◆ Every Federal, State, and local program serving mentally retarded persons should be required to make regular evaluations and issue public reports on the outcomes of service in relation to financial or social costs. The findings should be based on appraisal of services made by mentally retarded consumers or their personal representatives, by the serving agencies, and by independent judges or evaluating agencies.

Adequate research maintenance and utilization and manpower development to implement the most effective service delivery possible.

- ◆ Development of a national study and reference center on mental retardation and related matters. This center would serve two primary purposes: (a) as a focus of continuous study of the large-scale issues of principle and policy, linking all aspects of the problem toward the achievement of national goals; and (b) as a forum for the continuing intercommunication of all organizations, agencies, groups, and individuals in any way connected with the prevention of retardation or the delivery of services to mentally retarded citizens. Such an organization would be private, Non-profit, and independent of unilateral control by any of the specialized groups it might involve.
- ◆ Active and continuing consolidation, field testing, coordination and transfer of research findings on mental retardation to serving agencies and systems, training institutions, and other research centers should be systematically developed. This system should provide, through HEW, regional offices, and other channels, continuing technical assistance to State

and local serving agencies and training centers to assure the translation of new knowledge into manpower preparation, pilot service innovations, and long-range service development.

- ◆ The planning of manpower needs and development should be addressed immediately by HEW in collaboration with the States. Such a plan should (1) develop the means for long-range determination of manpower requirements under the existing state of the art of service delivery; (2) develop and promulgate long-range manpower development plans for the nation, including provision for new types of manpower as projected programs and future needs determine them; (3) provide for regular modification of these plans to incorporate new knowledge and technical developments; and (4) assure an adequate present and future supply of trained serving agents to meet requirements of adequate and humane serving systems.
- ◆ In order to carry out the necessary training and preparation of manpower to meet the needs in all parts of the country, HEW should develop a comprehensive program involving the full resources of higher education. Such a program should be designed to provide adequate manpower development to meet all the needs of mental retardation in each part of the United States on a long-range basis. It should use all feasible means of developing and utilizing the training resources in the educational institutions of each State and area through consortia, out-reach programs, in-service extensions or other means, in addition to traditional academic degree programs. Universities, public and private colleges, community and junior colleges should all be involved in these efforts, with the role of leadership and coordination designated on a basis appropriate to the characteristics and resources of each area. The scope of manpower concerns falling within this program would be limited only by relevance to the issue of mental retardation and related disabilities. It would range from workshops for the orientation and training of volunteer personnel, through the training of direct care personnel, to professional training of the most advanced nature for administration, research, teaching, and professional service functions.
- ◆ A significantly expanded effort should be made to involve large numbers of volunteers in many areas of service delivery. Volunteers should be recruited particularly among those portions of the population outside the work force, such as older Americans who can be expected to increase in numbers significantly in the next quarter-century. Volunteer services can be developed both to complement and to supplement professional services.

International Relations

The attainment of a high and stable level of international relations in the cooperative resolution of the universal human problems of preventing and ameliorating mental retardation.

Full and continued participation of United States governmental and non-governmental agencies and organizations in international bodies concerned with mental retardation.

- ◆ Many United Nations agencies conduct activities relating to mental retardation, and the UN General Assembly itself adopted a Declaration of Rights of the Mentally Handicapped in 1971, with-United States support. The United States, under State Department leadership, should participate actively in furthering such efforts.
- ◆ The Department of State and other agencies of Government should maintain active interest and participation in the InterAmerican Children's Institute of the Organization of American

States, and support the involvement of U.S. citizens and groups in the activities of this organization related to mental retardation.

- ◆ The Department of State, HEW, PCMR, and other agencies of government should encourage and support membership and participation of United States citizens and groups in such non-governmental organizations as the International League of Societies for the Mentally Handicapped and the International Association for the Scientific Study of Mental Deficiency.

International assistance programs in mental retardation, designed to utilize the developed resources of any country in the organization and operation of mental retardation programs, techniques and personnel training in other countries.

- ◆ The activities of UN agencies as the intermediaries for requested assistance.
- ◆ The AID programs of the United States.
- ◆ Such programs as "Partners of the Americas" PREP program, involving relationships between North American universities and those of Latin America; and other relationships fostered by the Organization of American States.

The use of blocks of Fulbright-Hays Grants focused on the field of mental retardation.

- ◆ Short-term intensive workshops for personal training.
- ◆ Short-term intensive workshops on organizational and operational techniques in mental retardation programs.
- ◆ International exchange of films, film-strips, and slides with appropriately translated or subtitled explanatory text.
- ◆ The continued use of PL-480 counterpart funds as authorized by Congress on mental retardation projects by agencies of HEW.

Development and maintenance as basic policy of the United States of the international exchange of knowledge and information on all aspects of mental retardation.

- ◆ Participate in the conduct and the reporting of international scientific seminars and conferences sponsored by international organizations, universities, scientific and professional associations, and the like.
- ◆ Encourage and support the exchange of visiting groups of professionals, students, and citizens for better understanding of programs and facilities for retarded persons in various countries.
- ◆ Development of systematic means, under the leadership of the Library of Congress, for the exchange and translation of significant world literature in the field of mental retardation.
- ◆ Development of and support for an international information system in mental retardation.

- ◆ The International Directory of Mental Retardation Organizations and Activities-published as a joint venture of PCMR and the International League of Societies for the Mentally Handicapped. This needs to be maintained in a current state by periodic revision.
- ◆ Facilitation by the Department of State, in cooperation with HEW, PCMR, and other government agencies and professional organizations, of international research projects and seminars on significant problems in mental retardation, with the provision of supporting funds for organization and travel.

Public Attitudes

To achieve a firm and deep public acceptance of mentally retarded persons as members in common of the social community and as citizens in their own right.

Advancement of those values which emphasize the worth of every human being without regard to his material possessions, his job status, his productivity, his IQ, or his beauty, and which recognize the importance of diversity and the right to be different.

- ◆ Appropriate attention must be given to the areas of human values, of working with minority cultures, and of dealing with handicaps in the training of all new teachers, plus in-service training and the furnishing of curriculum aids in these areas for all present teachers.
- ◆ All students during the period of elementary and secondary education should be familiarized with the nature of handicapping conditions, both physical and mental, in the context of human values expected in the teaching environment previously discussed.
- ◆ Implementation of such a value-oriented approach to human relations in the education of children must apply at all levels.
- ◆ The Federal Government must continue to move forward under the authority of Part D of the Education of the Handicapped Act, which provides not only for the training of special education personnel, but also for the training of regular teachers in knowledge and sensitivity to the needs of the handicapped.
- ◆ The States should make training in human values and working with the handicapped a requirement in the certification of all teachers, not only of special education teachers.
- ◆ Schools of Education should develop units on human values and teaching the handicapped as part of the curriculum for all students.
- ◆ Courses on mental retardation and related disabilities should be included in the curricula of all students of medicine, dentistry, nursing, law and law enforcement, education, religion, psychology, social work, and any other field in which professional practice involves contact with developmentally impaired persons.
- ◆ The continuation and expansion of the "education for parenthood" program is essential, with inclusion of material on mental retardation.
- ◆ Civic organizations in each community should search for creative ways to enhance community regard for the teachers, social workers, recreation leaders, employment

counselors, residential aides, and all others who provide supportive service to retarded persons.

- ◆ ACTION, the National Center for Voluntary Action, and corresponding groups in every community should intensify the enrollment of volunteers in activities involving direct contact with retarded persons. In some cases, monetary incentives at least to cover expenses should be used to compensate, as in the Foster Grandparents program; in others, tax credits; and in still others, academic credit in field assignments.

A pervasive feeling of confidence that there will be a sufficiency of jobs, energy and other material goods to support a realistic surge toward humanized values. In that atmosphere, retarded and other handicapped persons will be regarded not as usurping competitors or as a burden or threat, but as needed participants in society, in the work force and in other community activity.

- ◆ Advocates for those who are retarded must cooperate vigorously in national and local efforts to achieve a society of sufficiency, and work for a climate of public confidence that such a society is on the way.

Use of changing trends and techniques in communications to promote (a) greater understanding of and appreciation for handicapped persons as neighbors, fellow students, fellow employees, and fellow citizens, and (b) understanding of the means of reducing the occurrence of mental retardation and other handicapping conditions.

- ◆ A continuing program, substantial in size and high in quality, for educating the general public via all communications media toward acceptance of retarded and other handicapped persons must be sustained.
- ◆ A continuing program, substantial in size and high in quality, for educating the public concerning the causes and means of prevention of mental retardation is essential.
- ◆ Every agency or organization concerned with mentally retarded people-national, State or local, public or private-must intensify its own informational efforts and build a community understanding component into every operating program.

The Role of Government

Equitable, coordinated, efficient and effective use of public resources in all mental retardation programs.

Coordinated and comprehensive planning of Federal, State, and local efforts in the area of mental retardation.

- ◆ The Federal Government should establish a continuing interdepartmental planning system on mental retardation, responsible for the preparation and promulgation of short-term and long-range plans. These plans should be based on joint assessment of needs and resources and the commitment of the participating departments to fulfill their respective responsibilities under the plans.

- ◆ State governments should establish comparable interdepartmental planning systems at the Governors' level, with similar responsibilities for the preparation and execution of plans for mental retardation programs among appropriate State agencies.
- ◆ The Federal, State, and local governments should guarantee to all programs in mental retardation, whose effectiveness in relation to planned objectives would require an extended period of operation, assured fiscal resources for the entire period of the planned effort.
- ◆ The Federal Government should create a national information system on mental retardation through which its departments and the States may get prompt and reliable intelligence on which to base their planning efforts.
- ◆ Federal, State, and local planning should enlist consumer panels, representing mentally retarded individuals themselves as well as their families and other representatives. These panels should be invited to participate in planning activities so as to assure that planning correctly reflects the interests of those persons for whom it is undertaken.

Assure, through Federal, State, and local organization and leadership, that program activities involving joint participation of two or more agencies serving mentally retarded persons will be planned and conducted in a coordinated and collaborative way.

- ◆ There should be established in each major department which provides services in relation to mental retardation, the position of an advocate, responsible to advise the department administrator of problems observed in the coordination of agency program efforts, to initiate efforts to resolve conflicts and effect solutions, and to call attention to program resources and authorities which may not be fully utilized in the best interests of those being served.
- ◆ Federal departments should, through bilateral or multilateral agreements, develop routine means to identify and resolve conflicts in policy, reflected in proposed or enacted law, proposed regulations, and instructional materials, which may result in one program's operations interfering with the realization of benefits from another.
- ◆ Each major department providing services should provide a case finding and access program to inform all known mentally retarded persons about services to which they are entitled, and guide them to sources of help in a fashion that assures they are actually offered such help.

Federal, State, and local accountability for the provision of effective services to mentally retarded consumers in an efficient manner and with due regard for the consumer's rights of redress.

- ◆ Federal, State, and local agencies should require of all case services provided or funded with their assistance, including those provided by private agencies, that a mutual agreement for the service and the purpose which it is to meet be negotiated with each person served, and that the degree of fulfillment of such agreements form one basis of determining the effectiveness of service. The confidentiality of such records must be safeguarded.
- ◆ Federal, State, and local agencies responsible for providing or funding services should establish systems for periodic monitoring of program achievements and case benefits, and for evaluating them against both program and fiscal standards.

- ◆ A prompt administrative appeals procedure should be offered by all Federal, State, and local agencies responsible for providing or funding services. If a mentally retarded person or his representative feels that he is not receiving services in accordance with his express need, he should be able to count on an impartial review and on an appropriate and prompt remedy.

1976

MR 76: Mental Retardation: Past and Present

Recommendations to the President

- ◆ Will the Incidence and Prevalence of Mental Retardation Be Substantially Reduced in the Next Quarter Century?

Progress toward the goal of substantial prevention depends on increasing the knowledge of causes and conditions of risk, eliminating known causes and avoiding known risks. The unknown is still far greater than the known, requiring continued investment in basic, targeted and applied research.

We know that the risk factors center in human reproduction and nurturance. Avoiding or minimizing these risks depends on a combination of public policy and individual responsibility.

Public policy impinges in terms of three massive and interacting lines of effort: 1) Public health services universally accessible, including genetic and reproductive counseling, maternal and child health programs, immunizations, nutrition control and control of environmental contamination. 2) Public social services involving the environment of child rearing and psychological nurturance and ultimately the whole environment of poverty, deprivation, and disadvantage. 3) Public education- all services including early infant and stimulation, maternal assistance, appropriate conditions of learning, individual assessment and programing, and systematic information at all levels concerning the hazards to normal development and how by they can be minimized.

All three of these public lines of effort are significant, not only to prevention of retardation, but to the enhancement of life for disabled people. The most important public policy decisions in these areas will affect both prevention and amelioration of retardation.

Individual responsibility is the necessary correlate to public policy in the prevention of mental retardation. In a democratic society, collective public policy sets a frame- work within which individual decisions can be made responsibly. This is based on the principle of informed choice, in which public services provide the widest and most effective sources of information possible and reinforce the choices made by individuals in relation to the risks of child-bearing and nurturance.

Given the best available genetic information, for example, prospective parents must weigh the hazards and choose to have or not to have children. Given maximum information concerning the condition of the fetus, it is the parents' decision whether to terminate pregnancy or continue to full term. Given the best information and assistance possible, parents or parental surrogates are responsible for creating the nurturance which will promote the best development possible with the least hazard to the child.

The challenge in the arena of prevention then, lies in the continued support of research to expand knowledge and its application; the implementation of public policies to promote the best conditions of conception, gestation, birth, childhood nurturance and learning; and in the stimulation of informed, responsible decisions by individuals in safeguarding the lives, health and development of children.

- ◆ Will the Mentally Retarded Person Be Accepted as a First-Class Citizen of the Community Regardless of the Nature and Degree of Disability?,

The goal of community acceptance, envi- prejudicial judgments, negative expectations by some of the pioneers in the field, tions have tended to accompany the dis-

was reversed during the late nineteenth and criminatory social attitudes toward early twentieth centuries, but has now mentally retarded people in society. emerged once again as the guiding concept The cure for these attitudes lies uli- directing governmental, judicial, profes- mately in direct personal contact under fa- sional and community policies. In large vorable conditions, far more than through measure it remains a concept, far from actu- persuasion. The American tradition of vol- alization. Only a small minority of the unteer service may offer the greatest American people fully recognize and un- promise to meet this difficult challenge.

derstand the full implications of such accep- Public Accommodation involves "making tance. It is often a thin veneer of conventional phraseology in the philan- room" for those whose disabilities prevent thropic and service-minded sectors of the them from acting in fully conventional community, easily dissipated when put to ways. Tolerance is not enough; accommo- the test of effective community action. The dation requires an active process of adjust- established methods by which, for a cen- ment and adaptation, so that the retarded tury, the community managed its retarded person may develop as far as possible citizens and which depersonalized, dehu- toward the conventional norm within the manized and disenfranchized them, have open community. The community must diminished but not disappeared during the then provide modified conditions to bridge past quarter century of more enlightened the gap between the individual's capability public policies. and the fulfillment of normal needs. This The extent to which such efforts to con- accommodation applies not just to a few social settings to which it may be assumed trol mental retardation have violated the that retarded people "belong," but is de- principles of the Constitution and the pro- signed to facilitate maximum mobility and fined moral ideals of the American people functioning within the community as a have been dramatized by recent judgments whole. of the courts, sought through class action Suits as a last resort. There are, of course, limits to the flexi- bility with which social structures can ac- But the challenge runs deeper than court commodate to broad individual decisions; the real issue is in public atti- differences. Special services and facilities tudes and the social behavior of people in are required when these limits are reached. day life. This aspect of public rela- No one, including those who are disabled, divides into three phases: public M'- has access to all possible opportunities in a ion, public acceptance and public community. Selection of where one goes nimodation. and what one does is a counterpart of indi- blic Information with regard to mental vidual difference and group membership, tion involves the dissemination of involving custom, preference and choice. ate knowledge concerning the na- The goal sought for retarded people is the ses and resultant conditions of elimination of these boundaries to freedom .retardation; the positive as well as of choice that are arbitrary and discrimina- ting characteristics of mentally re- tory or the result of thoughtless rigidity in People, including their variability; the operations of the community. prospects of their social, vocation- moral growth and development, ir capacity for degrees of responsi- ePence.

Public Acceptance involves attempts to change negative, rejecting attitudes into positive, accepting, realistic, tolerant and supportive ones. Stereotyped concepts

1978

MR 78: Mental Retardation: The Leading Edge - Service Programs that Work

1979

Mental Retardation:

Prevention Strategies that Work

1983

The Mentally Retarded Worker -
An Economic Discovery

1985

Mental Retardation: Plans for the Future

1986

Citizens with Mental Retardation:
Equality Under the Law

1987

The President's Committee on
Mental Retardation

1989

Citizens with Mental Retardation &
Community Integration

1991

Citizens with Mental Retardation and
The Criminal Justice System

1993

The National Effort to Prevent Mental Retardation and Related Developmental Disabilities

1994

The National Reform Agenda and Citizens with Mental Retardation
A Journey of Renewal for All Americans

1995

Collaborating for Inclusion

1997 *Voices and Visions: Building Leadership for the 21st Century*

1998

A Better Place: The Contributions of Americans With Mental Retardation to Our Nation's Workforce

Recommendations to the President

Consumer-Driven Services

- ◆ Include a clear legislative commitment toward consumer-driven services into all relevant Federal legislation. Any future expansion of Federal or State resources should be structured to allow consumer control over financial expenditures.
- ◆ Create and implement voucher, "Ticket to Work, or other new programs that will allow consumers maximum flexibility to control their financial resources, develop their own employment plans, choose providers and vendors, direct their job-seeking efforts and Pay for outcomes based on their satisfaction.
- ◆ Support consumers as they learn to make career choices over time. Make benefits counseling available to individuals using vouchers to make certain they are fully aware of the ramifications of employment choices on their disability and health benefits status.

Make Work Play

- ◆ Eliminate the current "earning cliff" in the Social Security disability program to allow consumers to attempt to enter the workforce without jeopardizing their financial futures. Entering the workforce should enable individuals to increase their earnings while lessening the need for income support.
- ◆ Redesign the work incentive components of the Social Security benefits programs so that they achieve their intended purpose. Work incentives should not be so complex that they cannot be relied upon, nor well understood.
- ◆ Allow consumers receiving services through the Home and Community Based (HCB) waiver to use more of their earnings to purchase housing, food, clothing and lifestyle benefits as they advance in their careers and take greater employment risks.

Maintaining Health Coverage

- ◆ Establish Medicare and Medicaid buy-in programs that will provide consumers long-term access to required health care. Create employment incentives for individuals who do not require income support, but need long-term health care to meet their medical needs while working.
- ◆ Create tax incentives that recognize the need of many individuals with mental retardation for personal assistance, specialized transportation, assistive technology and other special supports.

Make Programs Accountable to Consumers

- ◆ Allow consumers and families to establish a system of independent evaluations of local vocational agencies. The evaluation system should be focused on employment outcomes and consumer satisfaction, and not duplicate existing certification and accreditation efforts.
- ◆ Disseminate objective employment outcome and consumer satisfaction information to consumers, family members and advocates in local communities. Consumers who are risking their long-term benefits for a chance to return to work should have access to independent information on the quality of services delivered by potential provider agencies.
- ◆ Modify Federal and State rate setting and reimbursement mechanisms so as to compensate providers based on the quality of their outcomes as opposed to simply the amount of services they provide.

Access to Services and Supports

- ◆ Establish policies in each State and locality that promote, support, and share in the costs of reducing and eliminating current and future waiting lists for employment services. Establish specific targets to eliminate waiting lists for employment services within a reasonable period of time.
- ◆ Develop creative solutions to community-wide transportation problems. Encourage employers to develop cost-effective transportation solutions, including employer travel consortia, private transportation systems, or other strategies. Encourage State or local governments to provide a tax credit for employers who underwrite the costs of transportation for employees with disabilities. Request local communities to pool funding and transportation resources to maximize the cost effectiveness of specialized transportation services.
- ◆ Continue our current efforts to work collaboratively with computer hardware and software manufacturers to insure that current and future advances in computer applications are accessible to individuals with mental retardation, as well as all other individuals with disabilities.
- ◆ Develop partnerships among public schools, rehabilitation programs, businesses and other private entities to establish and operate programs that will provide personal computers to individuals with disabilities unable to afford them.

Effective Preparation for Employment

- ◆ Develop strategies for joint funding of transition initiatives at the Federal level that can serve as models for States and localities. Successful transition programs require the active involvement of students, their families, educational personnel, employers, and adult service agency representatives. All participants must be committed to sharing information, responsibility and resources to insure that all necessary components of a local transition

program are in place. The key to collaborative efforts is sharing of all resources, not just ideas.

- ◆ Ensure that students with mental retardation have continued access to community-based instruction, career exploration, vocational training, work experience and job placement experiences while in high school. Vocational preparation of students with mental retardation is in no way incompatible with education reform efforts underway in many States.

Careers Not Jobs

- ◆ Focus secondary special education programs on long-term careers and not merely entry level employment. Emphasis should be placed on movement through a series of positions, all directed toward the individual's career objective.
- ◆ Provide training for adolescents with mental retardation and opportunities to acquire self-determination and self-advocacy skills. Selecting a career and directing one's own transition process is a challenging activity for any adolescent. Local school district should insure that information and training in self-determination and self-advocacy skills is a component of the high school curriculum.
- ◆ Modify vocational rehabilitation and other Federal employment policies to emphasize long-term job retention, promotion and career advancement, as opposed to initial placement into entry-level employment or temporary, subsidized employment opportunities.

Eliminate Segregated Services

- ◆ Correct the existing imbalance in Federal expenditures that continue to emphasize segregated as opposed to integrated employment alternatives. Congress and the Administration should work to insure that Federal funds are exclusively used to support community integrated employment alternatives.
- ◆ Encourage and promote the efforts of individual States to expand community integrated employment opportunities. States should be allowed to use Federal funds to stimulate and support conversion of segregated day services to community integrated employment. Federal reimbursement mechanisms should include clear financial incentives for provision of integrated services.
- ◆ Eliminate inequitable reimbursement practices that create disincentives to conversion of segregated employment settings. Reimbursement rates should provide clear financial incentives for placement into community integrated employment settings.
- ◆ Support people, not service agencies. If an individual who is currently receiving services in a segregated setting enters a community integrated employment option, monies used to support the individual's participation in the segregated setting should follow the person into the employment setting. If an individual moves from one community to another within a State, funding for that person should move with the individual and be available to purchase the vocational services he or she chooses in the new community.
- ◆ Involve consumers and their families in the decision to convert an existing agency, the steps the agency will take to expand community integrated employment, the timeline for program

expansion, and the evaluation of program success. Consumers should not have major program changes thrust upon them without their full participation.

Access to Needed Services

- ◆ Insure that employment programs for adolescents and young adults with mental retardation don't exclude those individuals with the most significant support needs. Persons with significant disabilities are those who can benefit most from participation in supported employment and other integrated employment alternatives.
- ◆ Increase the participation of students with mental retardation in local programs established through the School-to-Work Opportunities Act initiatives in proportion to their participation in the overall school population.
- ◆ Increase the participation of adolescents with mental retardation in youth employment programs operated by the Department of Labor's Employment and Training Administration programs and the Department of Education's Office of Vocational Education.
- ◆ Provide individuals with disabilities and their families the opportunity to realize the full promise of welfare reform by having an equal opportunity for employment through State programs established under the Personal Responsibility and Work opportunity Reconciliation Act.

Access to Qualified Personnel

- ◆ Provide information and training on consumer-driven services directly to consumers, their families, and peer mentors. Training and dissemination resources should be focused on raising people's expectations of employment and meaningful careers and on helping them to secure the supports they need to achieve their goals.
- ◆ Require each local Social Security office to have an individual on staff who is thoroughly trained as a work incentive specialist(s) who can provide assistance to consumers throughout the entire process,
- ◆ Encourage local school districts and adult service agencies to target training efforts toward students with disabilities to enable them, to the maximum extent possible, to direct their own career preparation programs. Training efforts should focus on establishing career objectives, directing one's own transition planning meetings, understanding post-school services and effectively advocating for oneself.
- ◆ Establish subsidized training programs, tuition vouchers, and other "public service" benefits for persons who enter the roles of supporting employment outcomes for persons with mental retardation.

Support for Employers

- ◆ Expand the current Work Opportunities Tax Credit so that the economic incentives to employers are equivalent to that provided by the Welfare to Work Tax Credit.

- ◆ Provide employers convenient access to the information and technical assistance they need to provide training, support and accommodations to individuals with mental retardation on their workforce.

1999 The Forgotten Generation

Recommendations to the President

Employment & Economic Security

School to Work Transition Programs

- ◆ Make schools accountable for their transition efforts based on the outcomes of students with a philosophy of “ everyone graduates with a job.” Schools and cooperating agencies should receive recognition including financial incentives for individuals who are successfully placed into competitive employment Opportunities and sanctions for those whose transition programs wither. For schools that place little emphasis on transition or whose transition efforts consistently meet with little success, stringent measures should be taken to suspend or withhold federal funding until energies are refocused on generating successful outcomes for people.
- ◆ Develop individualized educational plans including plans for transitioning from school to work, for all high school students. Career development and transition plans for all students should be driven by the talents, interests and needs of the individual.
- ◆ Urge schools to put primary emphasis on providing training to prepare all students for successful careers. Upon transition, generic and specialized resources should be identified that provide continuing supports needed for the individual to pursue desired career moves.
- ◆ Increase the participation of individuals with mild cognitive limitations in school-related programs funded under the School to Work Opportunities Act, the Department of Labor's Employment and Training Administration programs and the Department of Education's Office of Vocational Education.
- ◆ Encourage individuals, family members, educational personnel, employers, and adult service agency representatives to work together to ensure that people have lifelong access to the community supports they need to pursue careers.

Building Partnerships

- ◆ Develop creative partnerships between individuals, schools, service agencies, businesses, industry and others to address the needs of people with mild cognitive limitations.
- ◆ Help employers develop effective strategies to employ individuals with mild cognitive limitations that are responsive to their specific needs. These supports might include, but certainly are not limited to, modified or expanded workplaces, job accommodations, assistive technology, employee training, mentoring programs, employee orientation, development of interdependent or shared jobs and the development of natural supports.

- ◆ Work with the National Association of Employment Assistance Programs and similar groups to enhance the focus on supports for people with mild cognitive impairments as part of their nurturance, of all employees.
- ◆ Expand and enhance school-business partnerships to include all students not just those without disabilities.
- ◆ Identify and replicate model programs that are working to develop long-term partnerships between the business communities and providers of supports. This enhances the capabilities of the workplace to embrace individuals with mild cognitive impairments.
- ◆ Expand the current Work Opportunities Tax Credit so that the economic incentives to employers are equivalent to that provided by the Welfare to Work Tax Credit.

Support for Employers

- ◆ Train potential employers, service providers, educators, and the general public to interact effectively, support and assist individuals with mild cognitive limitations.
- ◆ Provide employers convenient access to the information and technical assistance they need for training, supporting and accommodating employees with cognitive limitations.
- ◆ Expose the myths surrounding individuals with cognitive limitations and promote healthy, positive images and accurate information regarding these individuals and their potential to achieve successful employment.

Training and Support Programs

- ◆ Hold all government agencies and service providers accountable for high quality employment outcomes for individuals. Impose financial sanctions when programs consistently fail to improve the employment situation for individuals with mild cognitive limitations.
- ◆ Provide integrated, competitive employment opportunities for individuals with mild cognitive limitations.
- ◆ Assure that necessary training and supports, including life-skills and literacy training, are available in school and throughout life.
- ◆ Adopt the “Nothing about us without us” philosophy and promote the involvement of individuals with mild cognitive limitations in the design, development, implementation and evaluation of employment supports and services.
- ◆ Promote an array of demonstration projects and the use of their findings to remove the walls between funding streams.
- ◆ Assure that accessible, dependable public transportation systems, including paratransit systems, are readily available to individuals with mild cognitive limitations throughout the country.

Work Disincentives

- ◆ Develop strategies to move individuals from welfare to competitive employment using proven methods.
- ◆ Establish Medicare and Medicaid buy-in programs that will provide consumers long-term access to required health care.
- ◆ Enable individuals whose benefits stop due to employment to remain eligible for benefits should they lose their jobs and be unable to return to work in the future.
- ◆ Create employment incentives for individuals who do not require income support, but need long-term health care to meet their medical needs while working

Housing

Leadership

- ◆ Take swift and potent action to develop progressive policies regarding housing needs and community supports for individuals with mild cognitive limitations.
- ◆ Assure that the budget and all of the initiatives are in sync. For example, when supporting work incentives and tax credits so that people can become employed, expanding home/community options must include housing resources targeted to people with disabilities to match the employment initiatives, such as providing an additional 20,000 Section 8 vouchers.
- ◆ Convene key players to discuss the housing needs of people with mild cognitive limitations and advocate for more affordable housing options.

Public Awareness

- ◆ Expose the travesty that people with disabilities--even those earning minimum wage--are living in poverty and often cannot afford safe or adequate housing.
- ◆ Introduce information on and planning for housing as part of the high school transition process.
- ◆ Simplify the reading level of housing information papers and documents.
- ◆ Produce a yearly easy-to-read publication on how to access affordable housing and existing funding programs.
- ◆ Train housing program personnel on the needs of people with mild cognitive limitations.

Research

- ◆ Conduct a national survey on the housing needs of people including those with disabilities.

Build Coalitions

- ◆ Identify and promote opportunities for advocates, advocacy agencies, Public Housing Authorities, and local governments to work together to solve housing problems.
- ◆ Form state and local housing coalitions including self-advocacy and disability groups, provider organizations and others to influence how housing money is spent.
- ◆ Build on supports to coalitions to describe the needs of the various populations, teach citizens to access housing, work to influence the allocation of resources for safe, affordable housing and advocate for civil rights protection in housing.
- ◆ Encourage the disability community to actively participate in the Consolidated Plan (ConPlan) that cities and counties receiving Federal housing assistance are required to develop and update annually. The ConPlan is a comprehensive 5 year planning document that describes housing needs, market conditions, housing strategies, and outlines an action plan for investment of federal housing funds.
- ◆ Encourage service providers, disability groups, family, friends, and provider organizations to join low income housing coalitions at national, state, and local levels. Self-advocates should become active in these coalitions underscoring the theme, "Nothing About Us, Without Us." These coalitions embrace other populations, such as people on welfare, immigrants and the homeless, pooling resources and political power to become formidable in their influence.

Transition Planning

- ◆ Use IDEA and school to adult life transition planning to build in supports, including housing, for life after school and to prepare families and students for change.
- ◆ Develop transition planning specifically for foster care children with cognitive limitations in the areas of community living and housing as this group faces particular challenges in transitioning to adult life.

Federal Housing Issues

- ◆ Identify and evaluate positive state and federal practices in supports for persons with mild cognitive limitations affected by welfare reform.
- ◆ Encourage state governors to include work and housing initiatives for people with disabilities in their National Governors' Association agenda.
- ◆ Provide State Legislators examples of good models of housing development ideas from other states.
- ◆ Increase the stock of low-income housing. Reverse the trend that has taken money out of housing programs to help people with disabilities.
- ◆ Support a home of your own program that significantly expands the potential for home ownership by individuals with mild cognitive limitations.
- ◆ Link housing (Section 8) vouchers to SSI or to Home and Community Based Waiver Supports so when someone qualifies for one service, they qualify for all.
- ◆ Move beyond HUD to reach whatever federal resources can help to increase funding for affordable housing.
- ◆ Work with corporations and lenders to help them understand the needs of individuals with mild cognitive limitations.
- ◆ Move beyond HUD to reach whatever federal resources can help to increase funding for affordable housing.
- ◆ Work with corporations and lenders to help them understand the needs of individuals with mild cognitive limitations.
- ◆ Increase the flexibility of eligibility for Fannie Mae loans.
- ◆ Increase participation of private loan institutions in developing loan products for people with disabilities.
- ◆ Assure that the 20% of TANF dollars that can go to family supports is used creatively for housing.
- ◆ Raise the minimum wage and eliminate barriers to people saving money, so people can work their way out of poverty.

Community Living

Public Awareness

- ◆ Make the public and policymakers aware of the fact that people with mild cognitive limitations exist and need ongoing supports to achieve healthy, full contributing lives.
- ◆ Mount a publicity campaign to increase acceptance of people with disabilities across the country by promoting accomplishments of individuals with disabilities. This campaign should encourage community inclusion and include examples of people being included in housing, being good neighbors, contributing to their communities, embracing diversity, etc.
- ◆ Reach out to the public for input on these recommendations to the President. Ask that they be adapted into public policy at every opportunity.

Further Research and Education

- ◆ Educate private foundations about people with mild cognitive limitations, their needs that are not being met by federal and state resources, and how they can help.
- ◆ Promote research to identify more precisely the Forgotten Generation. There are many questions:
 - ◆ How many people fall into this population?
 - ◆ Why do people have the challenges they have?
 - ◆ How many live in poverty? What is the true economic impact?
 - ◆ What strategies could improve the situation?
 - ◆ Perhaps the most important question of all is: How can we encourage and support generic community services to reach out to meet the needs of all people including these with mild cognitive limitations.
- ◆ Present the findings from this research widely. Teach present and future professionals, educators, generic service providers and others about this population and the strategies that can alleviate the challenges that are faced.
- ◆ Assure that research conducted is designed with the input of individuals with mild cognitive limitations so that the strategies employed respect informed choice and personal dignity.
- ◆ Work with Health and Human Services to develop data on the TANF program and its activities in regard to people with mild cognitive limitations. Publicize the resulting information to all resources that can impact on public policy and enhance the lives of individuals with mild cognitive limitations.
- ◆ Encourage the Administration on Children and Families to invest in a survey to determine the specific outcomes for recipients of public benefits with mild cognitive limitations.
- ◆ Study the effects of federal and state higher graduation standards on youth with mild cognitive limitations.

Poverty

- ◆ Increase awareness within the Federal government and Administration about the millions of people with disabilities who live in poverty and who should have access to federal programs.
- ◆ Expand membership of coalitions looking at poverty at the community and state levels to include self-advocates, family members, friends and providers.
- ◆ Promote joint initiatives between developmental disabilities, vocational rehabilitation, education and social services around welfare to work.
- ◆ Establish cooperative demonstrations to work in waiver authority under 1115 of the Social Security Act.
- ◆ Add the infrastructure development to establish independence accounts through a funded Home and Community Based Waiver service.
- ◆ Raise the minimum wage to a livable wage and eliminate barriers to people saving money, so people can work their way out of poverty.
- ◆ Work with Administration of Children and Families to identify and encourage exempt uses of welfare reform funding for people with mild cognitive limitations.

Enhancing Self-Advocacy

- ◆ Create opportunities in local schools for students to learn about self-determination and making informed choices. Supports for helping people learn to be strong self-advocates should start in elementary school.
- ◆ Develop coalitions to build stronger self-advocacy networks on a local, state and national level. The Illinois Self-Help Center, designed to strengthen linkages and develop mutual support strategies, serves as a good model for these coalitions.
- ◆ Expand support for helping people to learn to be strong self-advocates, starting in elementary school.
- ◆ Simplify the reading level of applications, information papers and legal documents.
- ◆ Mandate that all disability and generic services funded through federal resources require the active involvement of individuals in the development, design and evaluation of the supports and services they receive. Assure that self-advocacy training is available so that people with mild cognitive limitations are able to effectively participate in driving the supports and services they receive.
- ◆ Encourage and support self-advocates in joining various advisory committees, coalitions, Boards and other community groups.

Community Supports and Service Brokerage

- ◆ Establish information and service brokerage supports that are available to all individuals regardless of their disability. Service brokers are independent contractors who are hired by the individual. Brokers generally assist people with disabilities and their families to plan for

the future, get information and identify resources and find service providers and sources for informal supports. They arrange for services, evaluate services and supports, and review the arrangements as needed to address the individuals' changing needs and life circumstances (Bradley, Agosta & Kimmich, 1999).

Brokers can help people to find suitable housing, find a job or make social connections. They work to expand the natural supports that people already have in family and friends. If people do not already have a circle of people who can support them, the broker helps to create one. These circles work with the individual to help them lead the lives they want to lead. As the circles of support begin to work well, members begin to take on roles that the broker played and the broker moves into the background, but is still available for assistance.

- ◆ Assure that service brokers are well trained in federal, state and local programs and resources, those designed for people with disabilities as well as those for the general population. People should be able to meet with a service broker at least once a year to learn about changes in Federal and State programs.
- ◆ Provide vouchers so that people with disabilities can hire service brokers who are uniformly trained. With a voucher, people can contract with any broker they choose. They also have the option to leave one broker and contract with another if they are not happy with the services they receive. Having control of funds more than any other factor, puts people truly in the "driver's seat" when it comes to designing their own futures and the kinds of services and supports they need to reach their dreams.
- ◆ Offer generic supports that are readily available that are not tied to organizations associated with disability groups so that people who do not wish to be labeled as disabled can get the supports they need without the accompanying stigma.
- ◆ Work toward more need-based rather than category-based services for everyone. Present services are based on categories of people with disabilities that are tied to particular funding streams. Need-based services would address specific problem areas for all people with needs, regardless of whether they have mild cognitive limitations or not.
- ◆ Assure the money follows the person. Currently the disability service system is based on a system of funding that reimburses providers for providing specific kinds of services. When a person leaves a program, the funding for services stays with that provider. The person may or may not be able to find alternative services that meet continuing needs. If the services are found, adequate funding may not be available to extend the supports to the individual. If the funds followed the individual instead, it would enable the person to purchase services that are consistent yet no more nor less than are truly needed to address individual needs.
- ◆ End waiting lists. Fully fund and/or improve equity in programs for people with disabilities so that those with mild disabilities are able to secure the supports that they need to become more independent and included in their communities.
- ◆ Establish stronger public/private partnerships between local government and private service providers.

- ◆ Foster interagency coordination for school-to-work transition. The Health Care Finance Authority, the Department of Education, Housing and Urban Development, the Social Security Administration and Rehabilitation Services Administration should work together to develop coordinated policies and benefits.
- ◆ Increase the availability of supports for individuals in community living, including personal assistance: a broad resource that can offer assistance in areas such as personal care, mobility, household affairs, transportation, community participation, communication and more. These supports can be secured through flexible cash subsidies such as family and individual support programs.
- ◆ Invest more federal funding to address access to public transportation. A reliable source of transportation is critically important to community inclusion, securing needed supports, economic self-sufficiency, full citizenship, self-determination and choice.
- ◆ Promote and secure universal health insurance to assure that people with mild cognitive limitations have full access to preventive and prescriptive health care.

Build Community

- ◆ Commission the development of a best practice guide on how to support people with mild cognitive limitations in the community and widely promote this guide.
- ◆ Sponsor a national conference on building community support structures for individuals with mild cognitive limitations. Foster communication among states to share model program ideas.
- ◆ Use the local media to match needs to available supports in community programs.
- ◆ Encourage community groups and associations to reach out to enroll people with mild cognitive limitations as members.
- ◆ Work with faith communities to build interest in providing supports to people with mild cognitive limitations to increase their competence and foster inclusion.
- ◆ Create more opportunities for individuals with disabilities to participate in established neighborhood activities, recreation, and groups dealing with community issues.
- ◆ Empower circles of friends in becoming advocates and assure that needed supports are found and maintained. A service broker is an excellent point person to develop a plan of action and facilitate this empowerment.
- ◆ Fund “citizen advocacy” style natural supports in which a person who is already living a successful, inclusive lifestyle in the community befriends an individual with disabilities to facilitate making community connections, identifying and using resources, fostering relationships and providing support and encouragement.
- ◆ Involve friends and family in planning for the housing, life-style preferences, needed supports, etc. of children and youth with mild cognitive impairments.

- ◆ Increase programs of mentoring younger students with disabilities in the schools. This can lead to building greater "circles of friends" in community so students with disabilities can lead inclusive lives as valued citizens as adults.

Criminal Justice

A Little Known Problem

- ◆ Convene a Summit on criminal justice issues. Invite key national, state and local players in the criminal justice system, such as the Department of Justice and the International Association of Chiefs of Police, and other national organizations of professionals in the criminal justice system. This Summit should be designed to educate about the many pitfalls the criminal justice system holds for individuals with mild cognitive limitations.
- ◆ Involve key advocacy, self-advocacy and criminal justice groups to work to place and keep this issue on a persistent national agenda for change.
- ◆ Encourage local and state advocacy and self-advocacy groups to pursue activities that can lead to systems change on the local level. Support this effort by providing workshops, conferences, publications and technical assistance.
- ◆ Explore a variety of ways to intervene early, before people with cognitive limitations enter into the criminal justice system. For instance, training people about situations that might lead to arrest, such as inappropriate touching, public vs. private sexual behavior and taking things when you do not have money can help to avert these behaviors and prevent trouble from occurring in the first place. Education about one's rights when arrested might help someone to ask for an attorney before questioning and prevent a confession to crimes that were not committed.

An Unprepared Criminal Justice System

- ◆ Fund the development of training modules for professionals in every aspect of the criminal justice system. The modules should provide information about people with mild cognitive limitations as victims, as witnesses and as offenders and include issues such as recognition, communication, management, alternative sentencing, protection of rights, and support for people as victims and witnesses.
- ◆ Mandate the use of these modules or comparable training as part of initial and ongoing educational requirements, including college coursework, judicial conferences, bar associations, police departments, etc.
- ◆ Encourage the criminal justice system to work with other agencies to effectively deal with the source of problems to keep people out of that system.

Alternative Dispositions

- ◆ Design a model system for developing alternative dispositions for people with mild cognitive limitations in the criminal justice system. This model should promote alternatives that are very flexible and highly individualized. Education and training should be provided to

individuals about their rights, how they can get formal and informal supports in the community and other issues pertinent to their situation.

- ◆ Insure that state juvenile and adult criminal law includes diversion programs for people with mild cognitive limitation that can be accessed by judges, probation officials and law enforcement personnel. Such diversion programs could include service brokerage and the use of flexible funds to pay for those supports necessary to keep individuals out of the criminal justice system.
- ◆ Create a system of court-appointed special advocates for individuals with mild cognitive limitations similar to those for abused children (CASA). This would assure that the individual understands rights, is aware of supports available, those involved are educated regarding the issues and assures that rights are protected.

The Magnitude of the Problem

- ◆ Encourage the Department of Justice to conduct a survey of criminal justice facilities around the country to identify people with mild cognitive limitations, including those from culturally diverse backgrounds.

Competency to Stand Trial

- ◆ Propose models to determine competency in individuals with mild cognitive limitations in criminal Justice standards.
- ◆ Research protocols to enable individuals with mild cognitive limitations to give truly informed consent. Assure that research designs are sensitive to individual privacy and dignity and to cultural issues.

Victims' Assistance

- ◆ Provide training and technical assistance for professionals in the criminal justice system when they encounter individuals with mild cognitive limitations as victims.
- ◆ Include individuals with mild cognitive limitations in counseling and classes designed to address victims' needs.
- ◆ Support people when they are assaulted or abused by caregivers. Such cases should be reported and prosecuted.
- ◆ Assure that people with mild cognitive limitations who are victimized are able to utilize restraining orders, as other citizens do.

Awareness of Rights and Resources

- ◆ Develop a training package for youth and adults with mild cognitive limitations that focuses on criminal justice system issues, such as: civil rights within the criminal justice system, how to reduce the chances of being a victim of crime, what kinds of supports there are in the community to help if you are arrested or become a victim of a crime, etc. Harassment and

hate crimes should be included in the issues addressed by the training. Make this training available in local schools and community colleges.

- ◆ Assure that current prevention programs on drugs and early parenting are available to students with mild cognitive limitations.
- ◆ Provide training for educators, counselors and others to prepare them to provide training to their students and to identify potential danger signs that might lead to problems with the criminal justice system. Address issues about people from culturally diverse backgrounds who have mild cognitive limitations in this training.

Participation as Citizens

- ◆ Educate the criminal justice system regarding the abilities of individuals with mild cognitive limitations as well as their rights under the Americans with Disabilities Act to participate as full citizens. Include in this training how accommodations, including the use of technology, can enhance participation of these citizens and others with disabilities as witnesses and jurors.

Citizenship and Civil Rights

Citizenship

- ◆ Distribute and explain the basic statement and four core principles in user friendly language sensitive to diversity of culture and language to state, federal, local government and other systems. Regulations, policies and practices must reflect the integration of the following core principles:
 - ◆ Individualization (taking into account each person's unique needs), not relying on labels or generalizations.
 - ◆ Independence, economic self-sufficiency and productivity, not dependence.
 - ◆ Inclusion and integration, not exclusion, isolation or segregation.
 - ◆ Empowerment (self-determination, real choice and full participation in and contribution to the community), not paternalism and charity.
- ◆ Build capacity for people to participate in the community at the earliest ages, through mentoring relationships and other empowering experiences.
- ◆ Assure that people with mild cognitive limitations have access to general curriculum on citizenship in school.
- ◆ Educate families how they can encourage active citizenship by participating in community activities as a family and serving as good models.
- ◆ Educate generic service systems about values and underlying realities of people with disabilities including focusing on community. Encourage these systems to provide services to these individuals.
- ◆ Build the capacity of generic systems to hear and address needs and desires of individuals with mild cognitive limitations and their families.
- ◆ Assure that the diversity of culture and language is respected and accommodated in content, communication, information, design, implementation and evaluation of all human service programs and community supports.
- ◆ Encourage advocacy groups to address issues of citizenship for people with disabilities, such as voting and participating in all levels of government.
- ◆ Examine models that support self-determination and promote replication of these models throughout the country.
- ◆ Sponsor a follow-up to the Forgotten Generation Summit to ensure that the work continues on these issues.

Advocacy

- ◆ Assure that all people-including those with limited incomes-have access to skilled counsel.
- ◆ Encourage University Affiliated Programs to work with law schools and communicate the core values of individualization, independence, economic self-sufficiency and productivity, inclusion and integration, and empowerment to them so that they are "user-friendly" to individuals with mild cognitive limitations.
- ◆ Educate people with mild cognitive limitations about the resources in their communities that can help in times of need.
- ◆ Encourage the development of a full range of advocacy services from peer support groups to skilled professional advocates knowledgeable about people with mild cognitive limitations.
- ◆ Empower people with mild cognitive limitations to become competent self-advocates through training, involvement in self-advocacy groups and support. This training should begin in school with opportunities to continue learning and supports throughout life.
- ◆ Assure that individuals who are self-advocates are able to have direct access to the judiciary.
- ◆ Develop systems to help people get information and advice on everyday matters, and support that can prevent issues from escalating to the legal system in many instances.
- ◆ Provide training in self-determination for young people and adults.

Consent

- ◆ Educate parents, professionals and the public about the right of individuals with mild cognitive limitations to make choices about issues that affect their lives and ways to assist people to make truly informed choices.
- ◆ Provide training to people with mild cognitive limitations in regard to self-determination including making choices.
- ◆ Require consent for medical issues including but not limited to sterilization, the use of behavior altering medications, surgery, experimental treatments, sexually transmitted diseases, restraints, aversive behavior treatments, denial of basic health care and lifesaving techniques, and testing and referral for organ transplants. Requiring consent carries with it the companion responsibility to provide full information about these procedures, including advantages, disadvantages, possible dangers and potential consequences in easy to understand language.

Guardianship

- ◆ Conduct a Department of Justice funded review and analysis of State guardianship laws with recommendations for how these laws might be revised. This study should identify alternatives to guardianship and how they can be utilized to provide necessary support without diminishing rights and privileges.
- ◆ Encourage the reform of guardianship laws that do not recognize the ability of people with cognitive limitations to be competent, and provide full due process in any type of

guardianship proceedings, including representation by counsel. This legislation should assure that the least restrictive option is used, encourage the use of accommodations (for disability and native language) and technology to enhance communication and understanding, and establish a strict process of reviewing the guardianship annually so that it can be modified as circumstances warrant.

- ◆ Mandate the use of simple, easy-to-understand language in forms and papers in the guardianship process.
- ◆ Provide training on self-determination for people with mild cognitive limitations. Self-determination includes issues such as managing money, making informed choices and how to find help when you need it.
- ◆ Provide training to individuals with mild cognitive limitations on issues related to decision-making guardianships, their rights in the guardianship process, and resources that can help them understand complicated legal papers and assure that their rights are protected.
- ◆ Provide education and training to families of individuals with mild cognitive limitations on issues of autonomy, self-determination and the dangers of over-protection.

Parental Rights

- ◆ Assure that people with mild cognitive limitations are able to participate in parenting classes while in school or as young adults.
- ◆ Offer Planned Parenthood services and parenting classes for individuals with mild cognitive limitations early in the child welfare process.
- ◆ Help people with mild cognitive limitations to identify and network with natural supports that may exist, such as extended families, neighbors, church members and others who might provide information advice or assistance on parenting issues.
- ◆ Assure that parents with mild cognitive limitations involved in custody and parental rights issues are provided access to legal counsel who are knowledgeable about the needs of this population.
- ◆ Increase affordable access to legal representation by increasing funds to legal services and protection and advocacy services. Tie this new funding to a mandate to use it for representation of individuals with mild cognitive limitations in civil matters, such as guardianship and parental custody.
- ◆ Encourage agencies to involve resources experienced in working with individuals with mild cognitive limitations in providing assistance with child care and child protective services.
- ◆ Urge the Department of Justice to aggressively examine cases on parental rights issues under Title II of the Americans with Disabilities Act.
- ◆ Educate child welfare agencies, family courts and others that individuals with cognitive limitations can be competent and effective parents, and how best to support these individuals.

Sexuality Rights

- ◆ Educate parents, professionals and the public as to the right of individuals with disabilities to express their sexuality.
- ◆ Assure that students with mild cognitive limitations are included in school educational programs about human sexuality. This education should also include planning for parenthood and protection against health concerns such as sexually transmitted diseases.
- ◆ Provide information and counseling to individuals with mild cognitive limitations about how to appropriately express sexuality, such as public versus private displays of affection, and sexual expression only when both parties are consenting and without using coercion.
- ◆ Educate those in the criminal justice system about issues of people with mild cognitive limitations around sexuality and to recognize that inappropriate sexual behavior may indicate limited information or understanding rather than criminal intent.
- ◆ Assure that sexuality issues are addressed in accreditation standards for services that provide supports to people with cognitive limitations.
- ◆ Develop policies that assure individuals with mild cognitive limitations have the opportunity to express sexuality and be protected against victimization.

Psychological, Familial & Spiritual Well-Being

Fragmented Support

Base all supports on the following principles:

- ◆ **Collaboration:** We need greater collaboration among Urban League, NAACP, self-advocates, health care, mental health, child welfare, disability, vocational rehabilitation, religious organizations, nonprofit groups, private and other pertinent groups. Such groups should have a shared responsibility and a shared capacity to provide supports to all populations. As their missions are parallel, their mission statements should reflect collaboration and an approach that emphasizes the whole person, not just one aspect of life. This collective mindset should include a shared recognition of the need to change the delivery and content of services.
- ◆ **A proactive, holistic approach:** All people are entitled to the services and supports that they need. Supports should offer a holistic approach with a focus on pro-action toward enhancing an individual's quality of life issues rather than belatedly reacting to the invariable crises that arise.
- ◆ **Self-determination:** Self-determination is a key to a person's happiness and should be available to all people, coupled with the opportunity to experience and practice full citizenship. Supports should seek to enhance the capacity for self-determination and full citizenship through a person-centered and life long focus that drives not only the quantity, but also the quality, of supports that are based in strong values. Professionals and educators

should be educated regarding these values and how to thread them through supports provided to individuals from this community.

- ◆ **Empowerment:** Supports should empower individuals to gain self-confidence and the ability to speak out and make decisions about their needs and desires, their hopes and dreams. The voice of the individual should be revered in directing a desired future and life goals.
- ◆ **High quality programs:** Mechanisms should exist that assure supports and services provided are of high quality, as defined by the people being supported. Research is needed to identify the magnitude of this population and their needs. Yet the strategies used to gain information should not be invasive and should respect the right of the individual not to participate. Participation must be an informed choice.
- ◆ **Cultural diversity:** Key among the principles that should be addressed is to strengthen cultural diversity. While this concept certainly contains aspects of race and ethnicity it must also embrace tribal issues and sensitivity to gender. Appreciation for the richness that comes from diversity and respect for the traditions within particular cultures are precursors for true inclusion and acceptance—a true community.
- ◆ **Family focus:** Just as supports often focus on part of a particular characteristic or need of an individual, so too are individuals supported without consideration of the role they play within their family unit. Particularly in relation to individuals with mild cognitive limitations, issues of family, marriage and parenting are profoundly important. Failure to recognize the impact of the individual on the family or that of the family on the individual results in insensitive supports that can be marginally successful at best. A primary goal must be to strengthen and solidify the family unit.
- ◆ **Spirituality:** There needs to be an increased emphasis on helping the spiritual community recognize and understand the needs of individuals with mild cognitive limitations.

Collaboration

- ◆ Develop a Collaboration Task Force comprising a major private network of families, self-advocates, advocacy groups, faith-based networks, corporate representatives, culturally diverse groups, tribal governments, Food and Drug Administration, representatives from the National Institute on Health, University Affiliated Programs, and others.

Among the recommended duties of this task force are to rewrite the Developmental Disabilities Act to embrace the principles noted above to facilitate collaboration and cooperation between the public and private sectors, implement the recommendations contained in this Report. This Task Force should work collaboratively to impact federal policy initiatives to support self-determination and empowerment, and encourage their empowerment and encourage their respective groups to register to vote and participate in the political process to improve the existing system.

Funding for Self-Advocacy

- ◆ Create Federal policy initiatives that support self-advocacy groups and activities that enable people to gain in self-knowledge. Self-advocacy groups enable people to learn about their rights and how to speak out for those rights.

Funding should be made available to self-advocates to stabilize existing groups and enable them to continue and expand their present supports and to create and maintain new groups. Representatives from these groups should develop a national agenda and be encouraged and supported in their efforts to fashion a more value-based, respectful and supportive service system.

- ◆ Educate policymakers about the importance of putting money into self-advocacy efforts. Funding should also be forthcoming to support activities that enable people to gain in self-knowledge, explore their heritage and embrace cultural traditions.
- ◆ Create a series of peer-to-peer teaching videotapes. Support individuals with mild cognitive limitations to talk about the issues on videotapes and share their ideas about how to improve supports, become more empowered, speak out more confidently and other aspects that help to educate their peers and others.

Universally Designed Resources

- ◆ Increase the ability of the Temporary Assistance to Needy Families (TANF) program to respond to the needs of people with mild cognitive limitations. Those implementing the TANF program should look to the disability community for effective strategies on how to address the needs of individuals with mild cognitive limitations. TANF should also recognize that the families of individuals with mild cognitive impairments have needs beyond those necessary to get and keep a job and address those needs.

Public Education

- ◆ Sponsor a series of regional conferences to address issues of people with mild cognitive limitations on a broad basis and with the active collaboration of a broad array of partners in the public and private arena. Self-advocates should be leaders in these conferences.

Limited Knowledge of Resources

- ◆ Create a national institute or clearinghouse. A repository of materials about collaboration and aspects of building supports for people with mild cognitive limitations, their families, and their psychological, familial and spiritual well-being. Existing clearinghouses should be identified and contacted to avoid duplicative efforts.

Health & Physical Well-Being

Sensitivity Issues Cut Across Health Services

- ◆ Train and encourage health care professionals to be sensitive to issues of race, ethnicity, diversity and culture, as they are relevant throughout the health care arena.
- ◆ Educate health care professionals about the concept of self-determination and of how to help people-including those with mild cognitive limitations -to make truly informed health care decisions.
- ◆ Encourage those in the health care industry to have a holistic approach to health care, with sensitivity to the role that a person's overall quality of life plays in their health and physical well-being.

Socialization

Urge policymakers, legislators and insurance providers to collaborate to provide resources to support alternative funding for social supports for people with mild cognitive limitations.

Develop and implement curricula to train providers to address comprehensive psychological factors including sexuality and developmental life span issues of individuals with mild cognitive limitations.

Assure that services provided in community based settings supports quality of life. Such services should assure the participation of consumers/providers in identifying socialization activities that are developmentally focused, and age and gender appropriate.

Surveillance

- ◆ Assure the federal government develops sampling strategies, questions and survey vehicles in studies of health service access and quality that include adults and children with mild cognitive limitations. Such efforts should be achieved through an interagency effort involving the Department of Health and Human Services, the Social Security Administration, and the Department of Education, collaborating with advocates, consumers and organizations of professionals.
- ◆ Develop state-based individual-related surveillance through the linkage of agency databases.
- ◆ Establish within states interagency committees that include advocates and consumers, to explore the feasibility of linking databases that can address risk factors, identify prevalence, service use, outcomes, secondary conditions, etc. Participants may include special education, public health (birth and death records) Medicaid, vocational rehabilitation, mental health, mental retardation. Critical issues include protection of individual identity, the disinterest of needed participants, and varying diagnostic practices. Consumer involvement is critical to guide the process and govern the use of data.

**A CHARGE WE HAVE TO KEEP – A Road Map to Personal and Economic Freedom for
Persons with Intellectual Disabilities in the 21st Century**

Recommendations to the President

Public Awareness

- ◆ The PCPID invites and encourages you, Mr. President, to participate as the Committee's spokesperson in a national campaign specifically targeted to school-age children and employers to change negative public attitudes toward people with intellectual disabilities. The campaign should include a variety of media, including public service announcements, print and television features, and a web directory to assist employers to identify individuals with intellectual disabilities who are seeking employment. The Committee is eager to collaborate and is prepared to partner with corporations that already have had positive experiences hiring individuals with intellectual disabilities.
- ◆ The Committee is partnering with the Special Olympics to change negative public attitudes toward people with intellectual disabilities.

Performance Management

- ◆ Establish a strategic partnership with the Office of Management and Budget, an appropriate non-governmental agency, and with the PCPID and other relevant federal agencies. The partnership would create a set of practical performance measures for agencies that administer federal programs that have an impact on people with intellectual disabilities to hold them accountable for the advancement of outcomes that improve personal and economic freedom. These measures and performance indicators should be comprehensive, consistent, and complementary.
- ◆ Apply an enriched PART to 20 percent of the government's generic and disability specific programs each year, beginning in FY 2004, with follow-up recommendations to address poor performance, and an annual report to Congress on the status of the improved program performance and outcomes.
- ◆ Urge Congress to conduct at least annual oversight hearings in the House and Senate to assess cross-agency performance with the advancement of outcomes that improve personal and economic freedom for people with intellectual disabilities. Such joint hearings should extend beyond traditional lines of authority to embrace a holistic view of individual and family support that analyzes relationships among tax, finance, economic, education, health care, and workforce policies.

Education and Transition from School to Work and Adult Life

- ◆ Develop meaningful assessments and accountability by establishing an Intra-Agency Task Force, which would be facilitated by the U.S. Department of Education and include national experts, to provide ongoing guidance to states on universally relevant standards and

appropriate assessments for students with intellectual disabilities under the No Child Left Behind Act.

- ◆ Support and promote the idea that the Jobs for the 21st Century initiative should improve reading instruction, acquisition of reading skills, improvement in post-secondary outcomes and improvement in post-secondary employment opportunities for all individuals with intellectual disabilities.
- ◆ Develop relevant standards that apply to skills and competencies required in the work setting through a collaboration with the U.S. Departments of Education and Labor to apply the findings of the 1991 Secretary's Commission on Achieving the Necessary Skills (SCANS).³⁸
- ◆ Support quality teacher training and professional development to help all teachers learn to elevate the achievement of all students, including students with intellectual disabilities.
- ◆ Increase post-secondary opportunities by providing opportunities for students with intellectual disabilities.
- ◆ Develop a seamless pre K-16 system of instruction and support to remove barriers that limit the ability of federal resources—including Social Security, Medicaid, special education, vocational education and other general education and human services resources—to be pooled with state and local funds to support students with intellectual disabilities while in high school, as they enter the workforce or post-secondary education.
- ◆ Foster community-based initiatives, as part of the Jobs for the 21st Century initiative, that lead to improved employment and post-secondary outcomes for students with intellectual disabilities.

Employment and Asset Development

- ◆ Authorize a streamlined process and accelerated timetable for states to secure approval of a dual waiver through the Social Security Administration and the Centers for Medicare and Medicaid Services that provide incentives to work, and accumulate assets for individuals with intellectual disabilities without losing their eligibility for benefits.
- ◆ Propose the establishment of Qualified Disability Savings Accounts (QDSAs) to encourage individuals with intellectual disabilities and their families to participate in long-term planning and savings, which will advance personal and economic freedom. Moreover, a QDSA would not exclude a person from receiving government benefits.
- ◆ Explore the structure of current Individual Development Accounts (IDAs) to determine whether they would require modification for qualified persons with intellectual disabilities to use as a savings account. Expand the opportunities to save for purposes based upon an individual's own needs without losing benefits.
- ◆ Establish a strategic partnership with the U.S. Departments of Labor, Education, Transportation and Commerce, the Centers for Medicare and Medicaid Services, the Social Security Administration, the Equal Employment Opportunity Commission and the Small Business Administration to promote employment of people with intellectual disabilities. In concert with the PCPID, these eight federal agencies have the expertise and experience to

leverage current employer relationships to stimulate new investment and support of individuals with intellectual disabilities in the workplace. An appropriate agency, like the Department of Commerce or Labor, should assume the leadership role in convening five forums concerned with employment of people with intellectual disabilities.

Forum 1: Convene a forum of small business leaders to promote a better understanding of the strengths of people with intellectual disabilities as employees and to discuss and resolve current issues concerned with employment of people with intellectual disabilities in small business establishments.

Forum 2: Convene a forum of large business leaders to promote a better understanding of the strengths of people with intellectual disabilities as employees and to discuss and resolve current issues concerned with employment of people with intellectual disabilities in large business establishments.

Forum 3: Convene a forum of human resources leaders to discuss and resolve current issues concerned with employment of people with intellectual disabilities, including appropriate announcements for jobs, appropriate application forms for employment, appropriate techniques for recruitment and selection of employees, appropriate pre-employment education and on-the-job training opportunities for improvement of performance by employees with intellectual disabilities, and other areas as may be identified.

Forum 4: Convene a forum on network capacity building, at the local level, with voluntary organizations for developing knowledge and skills for individuals and families on how to enter the job market and develop desirable personal contacts and supports.

Forum 5: Convene a forum of leaders from the transportation industry, advocacy organizations for people with intellectual disabilities, rehabilitation service organizations and federal agencies to develop initiatives targeted at improved access to transportation systems by people with intellectual disabilities. Access to transportation is pivotal to the employment, medical and health care, and education of people with intellectual disabilities.

Family Services and Supports

- ◆ Authorize a streamlined process and accelerated timetable for states to secure approval of a dual waiver through the Social Security Administration and the Centers for Medicare and Medicaid Services that provide incentives to work and accumulate assets for people with intellectual disabilities without losing their eligibility for benefits. This recommendation is repeated because it was developed by both the Subcommittee on Family Services and Supports and the Subcommittee on Employment and Asset Development.
- ◆ Establish an Interagency Task Force on Developmental Health that is facilitated by the Centers for Disease Control and Prevention with the PCPID, and includes representatives from the Centers for Medicare and Medicaid Services, the Administration on Developmental Disabilities, the Bureau of Health Professions, the Agency for Health Research and Quality, and private sector organizations.
- ◆ Commission longitudinal studies to: 1) design new financing options and assess their impact on service access and delivery to persons with intellectual disabilities, and 2) examine

provider attitudes, behaviors relative to inclusion of persons with intellectual disabilities in community-based and private practice settings.

- ◆ Relieve restrictions for meeting Medicaid eligibility for persons with disabilities when family members work by raising the income threshold for Medicaid eligibility.
- ◆ Convene a “White House Conference on Respite Care” to identify model service approaches that benefit families with members with intellectual disabilities.
- ◆ Conduct housing demonstration projects that include support services for adults transitioning from in-home dependent care to independent living environments. Encourage the Department of Housing and Urban Development (HUD) and the Centers for Medicare and Medicaid Services to collaborate with states to test affordable and accessible community housing models that promote independence and offer supportive services when needed.
- ◆ Support and promote respect for the civil rights, liberties and dignities of people with intellectual disabilities, which need to be respected in the environment of anti-terrorism tactics and strategies as developed and practiced by the Department of Homeland Security and related agencies.

Assistive Technology and Information

- ◆ Support the establishment of a network of “Research Centers of Excellence in Technology and Intellectual Disabilities” to engage in research and development on new technologies to improve the quality of life, wellness, and independent living of people with intellectual disabilities.
- ◆ Encourage White House leadership to convene a meeting of relevant agencies, including the Departments of Labor, Education, Transportation, Commerce and the Equal Employment Opportunity Commission, to promote access to technology which advances the employment opportunities of people with intellectual disabilities.
- ◆ Convene a forum, coordinated by the PCPID, to identify new and improved strategies to stimulate manufacturers’ investment in design and development of products that advance independence and the productivity of people with intellectual disabilities. The PCPID urges that a major emphasis be placed on the creation of a common architecture in the development of assistive technology. In addition, emphasis should be placed on the creation of synergy between government funding and assistive technology access and use in the home, workplace, and community.
- ◆ Encourage the Departments of Education and Labor to fund a series of demonstration projects that emphasize public and private sector coordination and investment.