



# **The President's Committee on Mental Retardation - 1987**

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## **REPORT TO THE PRESIDENT**

- The President's Committee on Mental Retardation 20th Anniversary Symposium

- The National Strategy Conference on Mental Retardation and Mental Health

- The National Conference on State Planning for the Prevention of Mental Retardation and related Developmental Disabilities



# Preface

The President's Executive Order of May 11, 1966, establishing the President's Committee on Mental Retardation (PCMR), and subsequent Presidential Executive Orders, have directed the Committee to submit an annual report to the President on the status of mental retardation in the nation.

The current report provides highlights of three conferences held during Fiscal Years 1986 and 1987 and extends building blocks of knowledge and innovation that have typified the work of the Committee over the past two decades. To commemorate this span of time, a special Twentieth Anniversary Symposium was held to review the gains and plan for the future. Appropriately, its theme was, "Maximizing the quality of life for individuals with mental retardation and other developmental disabilities."

The symposium reviewed the significant accomplishments of the past twenty years with a forward view of issues needing attention as we build on past and current approaches to rights and protections, community living, education, employment, and the prevention of mental retardation and related disorders.

The PCMR sponsored a National Strategy Conference on Mental Retardation and Mental Health in Washington, D.C. The purpose of this conference was to bring together our nation's leadership in the fields of mental retardation and mental health in order to delineate the state of the art relative to the diagnosis, care, and treatment of citizens with mental retardation/mental illness, as well as to chart a national course for the support and integration of citizens with these challenging needs into the confluence of family and community life.

The PCMR recognized that citizens with these needs constitute one of the most underserved and, at times, forgotten segments of the population. With this in mind, the PCMR called together governmental, professional, and parental representatives from across the nation to define the nature and extent of the problem, programs, and services that promise hope for substantive improvement in the quality of life of citizens with mental retardation/mental illness.

The Conference focused on several major themes: epidemiology, prevention, training, research, clinical diagnosis and treatment challenges, issues centering on the family system, community treatment-management alternatives, model service programs, and legal and legislative

barriers and supports. To analyze these critical issues, the PCMR invited academic, governmental, and parental experts from across the nation for this national conference. Each of the major themes was reviewed, analyzed, and critically questioned through individual presentations, panel discussions, and audience participation. Although, there was consensus on most basic issues and suggested strategies for change, a few issues created debate and the need for further study and analysis.

In the area of prevention, another major conference was held which focused on "planning at the State and Territorial level." To assist the States in preparing meaningful approaches to this cost-effective strategy, the Committee published a document entitled, *A Guide for State Planning: For the Prevention of Mental Retardation and Related Disorders*. This guide is a useful resource for the States as they write or review existing plans for prevention programs. This effort, it should be noted, is a part of the Federal prevention initiative within the U. S. Department of Health and Human Services in conjunction with the Surgeon General as directed by the President.

Currently an estimated six million Americans<sup>1</sup> of all ages experience mental retardation, and every five minutes another child is born with this disorder.

Mental retardation and related difficulties present major social, educational, health, and economic problems for our nation. We have also learned that fifty percent of all cases of mental retardation can be prevented through known intervention strategies such as proper nutrition, immunization, genetic counseling, early treatment of diseases, and alcohol, drug, and child abuse prevention, to name a few.

In addition, effective prevention programs will reduce personal loss, grief, and anxiety to individuals and their families who are affected by this disability, and will result in cost savings to our nation.

Albert L. Anderson, D.D.S.  
Vice Chairperson  
President's Committee on  
Mental Retardation

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<sup>1</sup>*The Problem of Mental Retardation*, DHEW Publication No. (OHDS) 79-21021.



# Acknowledgement

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Recognition is given to PCMR members Dr. Elsie D. Helsel, Chairperson, 20th Anniversary Symposium, Dr. Lee A. Christoferson and Dr. William Kerby Hummer, Chairpersons, respectively, Subcommittee on Prevention, and Vincent C. Gray, Chairperson, Subcommittee on Family and Community Services, for their leadership in development of the individual conferences; and PCMR staff who served as project officers for the three national conferences: Laverdia Roach, Coordinator, Subcommittee on Prevention, who served as project officer for both the PCMR 20th Anniversary Symposium and the National Conference on State Planning for the Prevention of Mental Retardation and Related Developmental Disabilities; and Michael Albarelli and Judy Moore, who were Coordinators, respectively, for the Subcommittee on Family and Community Services, who served as project officers for the National Strategy Conference on Mental

Retardation and Mental Health.

Dr. George N. Bouthilet, Coordinator, Subcommittee on Full Citizenship, served as project officer on the contract for the preparation and editing of the manuscript for the Report to the President. Dr. Leonard G. Perlman, an independent consultant in the field of disability and rehabilitation, served as the contractor. He was charged with reviewing all conference materials and preparing the manuscript. Jean G. Gumerson, Chairperson, and the members of the Subcommittee on Public Affairs were responsible for reviewing the manuscript prior to publication.

Acknowledgement is given to all participants in the conferences and to all PCMR members and staff who assisted in providing support toward the success of the conferences, culminating in this Report to the President. Special note is taken of the work done by Jim F. Young, Deputy Executive Director, PCMR.

Vivian Bricklin Levin  
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# Highlights From the President's Committee on Mental Retardation 20th Anniversary Symposium

## Introduction

The 20th Anniversary Symposium was held on May 12, 1986, in Washington, D.C. Its theme was: "Maximizing the quality of life for individuals with mental retardation and other developmental disabilities." The papers presented at this meeting revealed careful research and provided bench marks whereby comparisons could be made ten and twenty years hence, and progress or the lack thereof noted. The authors of the papers were guardedly optimistic about the future and reminded us that much remained to be done to bring persons with mental retardation and developmental disabilities into the mainstream of community life.

## Background

This symposium sponsored by the President's Committee on Mental Retardation (PCMR) brought together a number of the nation's leaders in the field, including representatives of the academic and research community, advocacy and consumer organizations and government to review progress of the past two decades in the areas of prevention, research, legal rights, economics, services and programmatic trends.

## Paper Presentations

Brief summaries of highlights of the papers are presented in this section of the report.

## Rights, Responsibilities and Responsiveness

In a paper delivered by Henry V. Cobb, Ph.D., he noted that as members of the President's Committee on Mental Retardation, we have for the past twenty years responded to the mandate of our appointment to gather information from the entire country on the problems, needs and concerns of mentally retarded and other developmentally disabled persons and to report our recommendations to the President of the United States. We can look back over those twenty years of the Committee's activities and the many prior years of personal involvement with the rights and interests of people with mental retardation and

say, "we have indeed come far!" We have learned that the rights of persons with mental retardation are not a simple all-or-none matter achieved by declaration or even by a set of landmark legislative and juridical decisions, but are embedded in a complex interplay of social forces where efforts to improve the quality of life for these citizens meet with resistance in the historically established underlayers of attitude, custom, legal precedent and institutional rigidity derived from past attitudes.

The centerpiece of our approach was officially launched in 1975 and submitted to then President Ford in a report entitled, *Mental Retardation: Century of Decisions*. This report was based on the following fundamental premises:

People with mental retardation have the same rights, legal and constitutional, as every other United States citizen, including the rights of due process and equal protection of the laws.

People with mental retardation can be more independent and function more competently than is commonly believed—mental retardation and incompetency are not synonymous.

Full citizenship exercised by a person with mental retardation in a community setting is possible and in the public interest.

For the actual realization of their rights as citizens, persons with mental retardation require developmental and supportive services to bridge the gap created by their disabilities.

As an extension of these premises, the following rights have since been vigorously pursued and include:

The rights of due process and equal protection of the laws.

The right to appropriate educational opportunity in the least restrictive setting.

The right to residential programs and other services in a setting most conducive to development and independence.

The right to equal employment opportunity.

The right of equal access to medical treatment and service.

The right to equal protection in the criminal justice system.

The responsibility to help implement these rights is distributed across the depth and breadth of our society and includes a combined effort by the person with a disability, the parents, the lay community, the professional community, and the public authority at the local, State, and Federal levels. The momentum that has gathered over the past two decades is reflected in the following sections of this report to the American people.

### **Programmatic Trends for Individuals with Mental Retardation**

In a paper delivered by Elizabeth M. Boggs, Ph.D., she noted the trends over a twenty-year period showing major changes that have worked to help bring citizens with mental retardation and other developmental disabilities into the mainstream of community life. It should be remembered that these positive changes began to take shape long before the 1960's and continued positive actions are needed in granting full citizenship to persons with mental retardation and other developmental disabilities. Dr. Boggs listed some milestones of significance as follows:

#### **The 1960's**

The American Federal system entered a new phase where legislation established Federal-State-local relations in new fields of activity on a vast scale with a national purpose. In this new model, the Federal grant was conceived as a means of enabling the government to achieve its objectives, with national policies defined in very general terms by the Congress. A part of the Great Society actions by Presidents Kennedy and Johnson was the "equalization of individual opportunity." Some of the main goals and progress which related to direct services included the following:

Improve standards and develop a national system of accreditation.

Expand the hospital improvement program as applied to State-operated residential facilities.

Develop an insurance system to give parents a free choice in selecting residential services.

Bring mental health authorities into more active participation in developing programs for persons with mental retardation who are emotionally disturbed.

Make health and education services available to every child from birth as his or her legal right.

Develop fixed facility and mobile health, education and social service programs for rural areas.

Include the needs of citizens with mental retardation in model cities planning.

#### **The 1970's**

During the decade of the 1970's attention turned to institutional reform and the goals embraced community placement and the movement toward community living. In *Mental Retardation 1972*, PCMR quantified the goal by citing 186,700 persons residing in 202 public institutions with annual admissions of 15,000 and releases of 14,700, with a target of 62,000 returned to the community. Measured by reduction in census of State facilities for mental retardation, this goal was met by 1982. One cannot be certain that all who left the facilities returned to the community. Perhaps as many as 20 percent were transferred to intermediate care facilities or nursing homes. Best estimates show that between 69 and 70 thousand persons remained in facilities throughout the 1970's.

#### **The 1980's**

Programmatically, developments in the 1980's are being driven both by the wave of changing provider and consumer opinion about what should be done, and by the Federal legislation of the 1970's. It should be noted that the White House Conference on Handicapped Individuals set a new tone which became the legacy of the 1970's legislation and resulted in positive effects well into the 1980's.

The focus was on individuals, people who may differ from one another, who cannot be stereotyped, and who have unique potentials. The new approaches were individualized education programs, individual habilitation plans, individualized rehabilitation plans, discrimination outlawed against individuals, advocacy for individuals and finally self-advocacy. It was plain to see that the time and concepts embodied in the legislation of the 1970's had molded the programs and events of the 1980's.

#### **The Future**

A theme that pervades the future of this field is the interdependence of disabled persons and others as integration is increasingly practiced. In particular, persons

with disabilities cannot escape the impact of macroeconomic and demographic trends, especially with the shift in expenditures for social services. Our sights must continue to seek new methods and challenges to meet the coming century. We need, for example, to be attuned to the changing patterns of work for everyone, with greater specificity of job matches from the point-of-view of job satisfaction, with the importance of the non-wage related benefits of work, and the impact of technology and the transformation of the industrial economy into the information society.

A paper delivered by Robert M. Gettings on service delivery trends provided some interesting data showing the changes over the past two decades. At the time PCMR was initially established, most States supported few, if any, alternatives to placement in large publicly-operated residential facilities. Severely and profoundly retarded youngsters were routinely denied admission to public schools. The concept of a community-based group home was new and largely untested. While many States had a blueprint for the development of a comprehensive array of services, such plans were still on the drawing boards with a few community programs funded primarily through private sources.

Some of the notable changes included the following:

A gradual but steady decline in the number of persons with mental retardation residing in large, State-operated institutions. The average population served in State residential facilities dropped from a peak of almost 195,000 in 1967 to under 110,000 in 1984.

A corresponding increase in the number of persons with mental retardation residing in various types of community living arrangements. Surveys have shown that retarded persons living in small group residences nearly doubled during the five-year period between 1977 and 1982, from 22,449 to 42,018. As a result, the proportion of persons living in facilities with 15 or fewer residents increased from 16.3 percent of all persons receiving residential care in 1977 to 26.1 percent in 1982.

An expansion in the range, quantity, and quality of services provided through the public schools. During the 1984-85 school year, over 4.1 million children with handicapping conditions received special education services. In contrast, just prior to the enactment of the Education of All Handicapped Children's Act of 1975 (PL 94-142), there were 1.75 million children with handicapping conditions between birth and 21 years of age receiving *no* educational services and an additional 2.5 million receiving inappropriate services.

A growing emphasis on providing employment opportunities for adults with moderate to severe mental retardation in integrated work settings. A national survey by the National Association of State Mental Retardation Program Directors revealed that most States have a

strong philosophical, programmatic, and financial commitment to developing supported employment and programs that will allow persons with mental retardation to be employed in integrated work settings.

The above changes in direction and focus have had a major impact on the structures through which services are financed and delivered. Some examples include:

The establishment of clearly articulated, organizational entities to orchestrate the delivery of State local services. Most States have established a local or areawide service delivery network with a county or regional unit serving as hub of the network.

By 1982, nearly half (47 percent) of residents with mental retardation were being served in privately operated facilities. If we look specifically at small, community-based homes, the shift and progress is even more dramatic. In 1982, 92.5 percent of all retarded persons living in residential facilities with 20 or fewer beds were in homes operated by private agencies or individuals.

An expanded list of service options. Over the years, most States' mental retardation/developmental disabilities (MR/DD) agencies have added several new categories of residential and day services that are eligible for public support. These new service options have evolved to fill in the service gaps to assist service providers in meeting the specialized needs of persons with mental retardation.

The growing influence of Federal policy. Between 1977 and 1984, State expenditures for MR/DD services increased by 138 percent. Federal receipts of State MR/DD agencies, however, grew by more than 250 percent over this same period. As such, the Federal share of State MR/DD budgets rose from 27 percent in 1977 to 40 percent in 1984.

An expansion in the eligible target population. In response to the passage of the Federal Developmental Disabilities Act of 1970, over half the States modified their eligibility requirements to permit persons with developmental disabilities who do not have mental retardation to receive day and residential services provided or funded by the State MR/DD agency.

Rapid escalation in the per client cost of providing residential and day services. Between 1970 and 1982, the per diem cost of care in State mental retardation institutions skyrocketed from \$5,000 to \$32,000 annually. An examination of all outlays for all types of services supported by MR/DD agencies revealed that nationwide expenditures topped \$7.5 billion in Fiscal Year 1985, or more than double the amount spent eight years ago in 1977.

In developing effective service delivery systems, the following guiding principles should be included:

- Individually designed and executed programs. This should be a central focus in any organized attempt to assist persons with mental retardation.
- Maximum opportunity for personal growth and development, i.e., to assist every client in attaining optimal development.
- A diverse array of program alternatives is necessary.
- Integration of clients into the mainstream of society.
- Safeguard basic rights. This is especially important since many persons with mental retardation are unable to fully exercise their human and civil rights without assistance.
- High quality services are needed. All facilities and programs should operate in compliance with applicable Federal, State, and local standards.
- Access to a comprehensive and coordinated array of services. In addition to offering a wide diversity of service options, a service system must have established linkages to ancillary health, education, and other human service networks and be in a position to offer clients specialized generic services.
- The efficient and economical operation of service facilities and programs under its jurisdiction. A service system must have the capacity to use the resources at its disposal in a manner which maximizes the return on society's investment.

Robert Gettings summed up his findings by stating, "History teaches us that the solutions to our problems usually lead to new and unanticipated challenges. Therefore, our chances of success will be enhanced if we proceed with an open mind and a willingness to learn from our mistakes." It is imperative that we be prepared to adjust the current system to meet the new demands of the future and expected changes in economics, demographics, and attitudinal shifts and competing values.

### **Research and Prevention**

Richard L. Masland, M.D., pointed out that in a survey that he conducted in collaboration with T. Gladwin and S. Sarasen in the mid-1950's, mental retardation had numerous problems; these included the following:

- Few of our large training centers for citizens with mental retardation were located in close proximity to our university and medical centers.
- Much of our information regarding social and environmental factors was questionable because retrospective data was unreliable, and pathological

studies were of limited value because no history of causation was available. There was a great need for prospective studies of mental retardation.

- Crucial questions remained regarding the issues of the problems of pregnancy and the care of the newborn. These problems cut across disciplinary lines.
- We noted that these issues of mental retardation extended broadly throughout science, and that solutions would need both laboratory and clinical investigations.

Dr. Masland noted that the challenges outlined above have essentially been met thanks to the support of both the public and private sectors and the leadership of the President's Committee on Mental Retardation. For example, there are now 47 University-Affiliated Programs (UAPs) designed to bring the problem of mental retardation and other developmental disabilities into the mainstream of university training and research. The Kennedy Foundation has established a number of multidisciplinary programs within our most prestigious universities. Under Public Law 88-196, twelve multidisciplinary research centers were created whose central focus is basic research into mental retardation. In the related field of child neurology, there are now over 500 well-trained specialists. Since 1958, the National Institutes of Health (NIH) have engaged in a collaborative perinatal project seeking answers to better understanding of the progress of pregnancy and its effect on the newborn. Since the early studies, we have gained much knowledge to supplement or replace previously weak concepts of perinatal factors causing mental retardation. The positive effects of our inquiries have been exciting and illuminating. There has even evolved an entirely new field of neonatology to better understand every aspect of pregnancy, delivery, and child development. Currently, almost every major university-affiliated program has a Neonatal Intensive Care Unit with many also having active multidisciplinary research teams.

To add to the fund of knowledge in basic research in mental retardation, the creation of the National Institute of Child Health and Human Development assisted with a focus on research on pregnancy and child development. Much research has also come from our studies of the nervous system and its diseases through the support and research efforts of the National Institute of Neurological, Communicative Disorders and Stroke.

The past twenty years have witnessed dramatic advances in our ability to control some causes of mental

retardation. Specifically, we have practically eliminated rubella, kernicterus, cretinism, and phenylketonuria and markedly reduced the impact of post-natal infections. With all these advances, however, it is unlikely that there has been any reduction in the overall prevalence of mental retardation. Improved techniques of perinatal care have prevented brain damage in many infants, especially low birthweight babies. However, the survival of very low birth weight infants who previously died has probably produced at least an equivalent number with neurological impairments who survive.

It is unfortunate that the gains made in the area of severe retardation are overshadowed by a lack of progress in the control of factors producing the mild to moderate forms of retardation. These factors are complex and, in some cases, poorly defined and include such areas as: unfavorable social and economic environments, poor maternal education, low maternal intelligence levels, teenage pregnancy, exposure to alcohol and other toxins, lack of prenatal care, and inadequate or improper nutrition. Dr. Masland stated that these factors will not be changed until there is a change in social attitudes toward pregnancy and the rearing of children. Perhaps research over the next two decades should focus on how this might be best accomplished.

#### **Prevention and Research: Behavioral Aspects**

In his presentation, Dr. Alfred A. Baumeisier noted that there are a great many sources of mental retardation known to professionals, policy makers, and other concerned citizens. Over 200 biomedical etiologies have already been identified and described in the literature. Additional biological and environmental causes continue to be discovered with great regularity. The Fragile-X Syndrome, for example, probably accounts for many who previously would have been diagnosed a few years ago as "unknown prenatal influences."

Evidence is becoming increasingly abundant that multivariate explanatory models involving biological, social, and ecological variables linked together in a common matrix will ultimately provide a much more valid and useful basis from which to generate cause and effect as well as intervention and prevention strategies. We need to understand that the uncertainties of etiology, symptomatology, and treatment of mental retardation will not yield to simplistic unidimensional models.

Because social, cultural, and economic divergencies are so deeply ingrained in our society, they are difficult for the researcher and the practitioner to isolate and control. In addition, research yielding definitive results in this area is exceedingly difficult to conduct. Despite this factor, evidence gathered over the past five years indicated that these elements may be the main factors associated with mental retardation, learning disabilities,

and affective disorders and may contribute to severe brain damage and cerebral palsy as well. Despite the difficulties inherent in this type of research, we have amassed a great deal of knowledge from which to continue our search. Some of these areas include:

- Teenage pregnancy—While teenage births accounted for 13 percent of all births in the United States during 1983, their infants represented 20 percent of all low-birthweight babies. There is, of course, a well established link between low-birthweight and a greatly elevated risk of infant mortality and other physical problems, including mental retardation.
- Prenatal care—There is considerable evidence that timely and adequate prenatal care is a major influence in reducing preterm and low-birthweight deliveries, thereby decreasing the risk of infant mortality and morbidity. While the greatest risk is borne by the poor, the disadvantaged, and the disenfranchised, in human and financial terms the cost is distributed over our entire society. One positive approach is to educate adolescent and poor mothers as to the need for proper prenatal care.
- Prenatal exposure to environmental hazard—A number of conditions involving both biomedical and behavioral aspects are sufficiently clear-cut to provide excellent models for understanding how quality of life might be improved through medical, behavioral, and educational intervention. One prime example of a cause of congenital malformations and neurologic handicaps is Fetal Alcohol Syndrome (FAS). The tragedy is that FAS is totally preventable. These are not new issues, but ones that have not, as yet, been addressed adequately.
- Socioeconomic status—Under this broad category there are usually three factors that are emphasized when we seek correlations with morbidity: income, maternal education, and occupation. While the etiology of some retardation can be traced to metabolic, genetic, and traumatic factors, and certain brain infections and toxins may cause severe cognitive impairment, a large group of children suffer from mental retardation due to biological and social variables operating in a dynamic and inseparable fashion. We now know that regardless of the child's health status at birth, the physical and social environment either enhances or reduces potential for normal development. Another factor related to cultural and ethnic effects is stress. The way a woman responds to her environment has an impact on pregnancy outcome. Some results of research, while not as yet conclusive, indicate a possible association between low-birthweight and activities that require long periods of standing and other significant amounts of physical stress.

- Additional data links psychological stress to a number of other undesirable pregnancy outcomes such as fetal distress, neonatal motor immaturity, perinatal deaths, and congenital anomalies.

Research and prevention continue to offer some difficult and exciting challenges, but we have come a long way in the past two decades—this offers much hope in seeking useful and dynamic interventions to some very complex problems.

### **Summary**

Dr. Leonard W. Mayo, in his summary of the Twentieth Century Symposium, indicated that, "Society has the responsibility to create the

conditions or settings in schools, workplaces, and the community at large. There is no question that there is a far greater understanding among the general public of mental retardation and other developmental disabilities than was true twenty years ago. The public image of a child and adult with mental retardation has undergone a positive change. This is due not only to professional efforts, but to the cooperation of the media and the success of people with disabilities themselves in fulfilling their role as citizens."

As we rejoice in the progress made, we must not forget that there are many who are not served and many more who are not served well. This is, as Dr. Mayo noted, the challenge of the future.

# Highlights From the National Strategies Conference on Mental Retardation and Mental Health

## Introduction

The President's Committee on Mental Retardation (PCMR) sponsored a major national conference on Mental Retardation and Mental Health on October 30-31 and November 1, 1985, in Washington, D.C. The purpose of the conference was to bring together our nation's leadership in the fields of mental health and mental retardation in order to better understand the state-of-the-art relative to the epidemiology, diagnosis, care and treatment of persons with the dual diagnosis of mental retardation and mental illness, as well as to chart a national course for the support and integration of citizens with these challenging needs into the mainstream of family and community life.

## Background

The President's Committee on Mental Retardation has long recognized that persons with mental retardation and a mental illness comprise one of the most under-served segments of the population. As such, the PCMR called together governmental, professional, and parent representatives from across the nation to define the nature and extent of the problem and to formulate specific recommendations for substantive improvement in the quality of life for persons with this dual diagnosis of mental retardation and mental illness.

## Paper Presentations

The conference focused on major issues including epidemiology, prevention, training of professionals, clinical diagnosis and treatment, research, the family, community alternatives, model service programs, and legal and legislative barriers and supports.

## Papers on Epidemiology

One of the papers noted that the incidence rate is dramatically higher than in the non-mental retardation population and that there are psychiatric syndromes which are unique to persons with mental retardation. In addition, past studies concerning the incidence and prevalence of mental retardation are in need of current replication with more recent data to study the special sub-population of persons with both

mental retardation and mental illness.

The focus of a number of authors was on the psychobiological and behavioral mechanisms which interrupt and/or interfere with the appropriate modulation of central nervous system functions. The recent availability of highly sophisticated laboratory technology now permits the direct study of human behavior which, until recently, could only be conjectured.

## Papers on Diagnostic Issues

Some papers indicated that psychiatric diagnoses are relatively easy to make in the individual with mild mental retardation, but diagnostic formulation becomes much more of a challenge in the person with severe mental retardation due to the communication and cognitive problems related to this level of functioning. A much debated issue was the common practice of attributing mental illness to mere everyday behavior problems and the concurrent problem of diagnosing only from observable behaviors alone. The need for appropriate diagnoses as a prelude to adequate treatment was emphasized.

The need to develop practical diagnostic tools and to apply such tools in the diagnostic and treatment process was also discussed extensively. It was noted that very few institutions of higher learning have dealt with or focused on this vitally needed training area for professionals.

## Papers on Treatment Issues

Papers dealing with psychoactive drugs gave rise to debates among the conference participants concerning the issue of the use of psychopharmacology versus the use of the principles of applied behavioral analysis. While these two approaches were often presented as a dichotomy, the debate resulted in the consensus that each has a role to play in the treatment process, and that one modality was not regarded as necessarily more restrictive than the other. In addition, it was felt that current research efforts tend to focus on singular treatment mechanisms such as the use of punishment to

control aggressive or self-injurious behaviors rather than more creative and holistic approaches.

### **Papers on Programmatic Issues**

Two basic themes were noted in this area of focus. The first was that persons with the joint diagnosis of mental retardation and mental illness are the most at-risk population to be placed in long-term institutional settings, often for life-long custodial care. The second theme was the paucity or unavailability of programs and services needed to meet the needs of this special population within the mainstream of community life. The greatest challenge as noted by the participants at the conference was on the ways to develop programs to prevent the institutionalization of this dually diagnosed person, and to find methods to bring those who are currently institutionalized back in the mainstream of family and community living. There was also consensus that programs and services for persons with mental retardation need to adopt non-rejection policies since it was noted that the dually diagnosed are the last to be served and the first to be rejected from community-based programs for persons with mental retardation.

### **Papers on Legal and Legislative Issues**

The emphasis of many of the papers was that persons with both mental retardation and mental illness have the same rights and privileges as any other citizens of the United States. Current laws for citizens with mental retardation and developmental disabilities apply equally to individuals with joint mental retardation and mental illness. It is unfortunate that these rights for the latter group are often obscured by the confusion of the dual diagnosis which results in interagency shuffles that leave the person poorly served by both systems involved. Additional legal issues focused on the misuse of psychoactive drugs and the systematic use of restraint and punishment in lieu of active and positive intervention strategies. The authors also encouraged further systematic analysis of the legal status of persons with mental illness and mental retardation in whatever settings they receive services or assistance.

### **Papers on Parental and Family Issues**

It was pointed out that families with members who have both mental retardation and mental illness are often left without adequate support from either system. Often these family members remain unserved or under-served or are sent to long-term institutional settings with little hope for amelioration

or return to family and community life. Parents having children with these special needs require a wide range of in-home and supportive services such as parent training and respite care in order to support rather than supplant the family. In addition, there is a strong need to prevent mental illness in the person with mental retardation through intervention programs with the person and his/her parents through the provision of supportive services as early in life as possible. Parent training and respite care for families were the two most often cited prevention strategies.

The papers presented at the conference covered a diverse spectrum of issues and potential solutions to the problems of mental retardation-mental illness. A sampling of the major findings and recommendations derived from the conference are noted under the specific topical headings that were discussed at this national meeting.

### **Epidemiology**

- Past studies concerning the incidence and prevalence of mental retardation are in need of updating. Recent data are critically needed to further study the special sub-population of mental retardation-mental illness.
- In the current state of major research, the focus is clearly on the psychobiological and behavioral mechanisms which interrupt and/or interfere with the appropriate modulation of central nervous system components.

### **Diagnosis**

- Diagnostic formulation becomes much more of a challenge in the person with more severe mental retardation due to the communication and cognitive problems related to this level of functioning.
- A much-debated issue is the common practice of attributing mental illness to mere behavior problems and the concurrent problem of dealing with observable behaviors alone, rather than underlying mental illness. Conference participants underscored the need for appropriate diagnosis as a prelude to adequate treatment.
- There is a need to develop diagnostic processes in order to treat the whole person.
- The need exists to develop practical diagnostic tools and to apply such tools in the diagnostic and treatment process.
- Most mental health and mental retardation professionals need more specific training and experience to

appropriately diagnose mental illness in the individual with mental retardation.

- Conference participants emphasized the need to provide training experiences for mental health and mental retardation professionals in the diagnosis and treatment of mental illness in mentally retarded persons.

### **Treatment**

- National attention needs to be given to the inappropriate use of psychoactive drugs such as their use as a chemical restraint, which is unrelated to any psychiatric diagnosis or treatment process. Similarly, the misuse of behavioral techniques as a systematic tool for restraint and punishment was heatedly debated. Others held that entire new treatment strategies need to be developed and researched to preclude the use of punishment as an accepted treatment modality.
- Current research efforts tend to focus on singular treatment mechanisms such as the use of punishment to control aggressive or self-injurious behaviors rather than more creative and holistic approaches.
- There is a national need to embark on more balanced and humanizing treatment approaches.
- A strong need exists to move away from historic assumptions upon which much research has been based and move toward the analysis and delineation of new treatment approaches based on this target population.

### **Programs**

- Persons with mental retardation-mental illness are the most at-risk population to be placed in long-term institutional settings, often for life-long custodial care, and there is a paucity or unavailability of programs and services needed to meet the needs of this complex group of citizens within the mainstream of community life.
- There is a need to define and develop programmatic mechanisms to prevent the institutionalization of persons with this dual diagnosis, and to find ways to bring those tens of thousands who are currently institutionalized back into the confluence of family and community life.
- The need exists to develop and support a range of community-based alternatives for these citizens.
- An array of programs and services that States and communities need to develop include models of acute psychiatric care and treatment, specialized educational and vocational programs, community

residential alternatives such as group homes and a number of supportive services such as day hospitals, counseling services, and family support programs.

- There is a national need to have various tertiary care centers that specialize in the care and treatment of the more acutely mentally ill.
- Tertiary care centers should be expanded to serve a three-part role of treatment, training, and research.
- Considerable discussion was held at the conference on the wisdom of avoiding separate services just for this specific target population.
- There is a need to consider the integration of persons with mental retardation and mental illness into existing programs for this dually diagnosed population.
- More generic mental health services should be made accessible and available for the psychiatric needs of the person with mental retardation.
- Community mental health services should be made available to persons with more severe mental retardation, i.e., generic mental health services.
- Mental health centers should engage in acute and follow-along care while mental retardation programs should focus on daily living activities and educational and vocational needs of the persons with this dual diagnosis.
- There are groups of persons who present unique service challenges such as those with personality disorders with resultant criminal justice system involvement. It was pointed out that even this population could be served in the community given highly specialized and supervised programs and services.
- Programs and services for the person with both diagnoses need to adopt non-rejection policies. It was often cited that the person with mental retardation-mental illness are the last to be served and the first to be rejected from community-based programs for persons with mental retardation.
- The high number of persons with mental retardation-mental illness in State institutions was an often-noted national problem. A corollary problem dealt with the person being moved back and forth from institutions for persons with mental retardation to institutions for persons with mental illness in a life-long cycle of non-treatment experiences.

- The most popular approach advocated was to treat the acute psychiatric needs of the mentally retarded in psychiatric settings and to meet their long-term needs in community programs for the mentally retarded person with secondary support provided by mental health systems.

### **Legal Rights and Legislation**

- The citizen with mental retardation-mental illness has the same rights and privileges as any other citizen of the United States, e.g., the right to be free from harm, the right to minimally adequate treatment, the right to live in settings that least restrict their freedoms.
- The "dual diagnosis" often results in interagency shuffling that leave the person with mental retardation-illness poorly served by both systems.
- There is the need to apply the same legal, legislative, and regulatory standards to the individual with both mental retardation and mental illness as to the person with mental retardation, e.g., the Developmental Disabilities Assistance and Bill of Rights Act, and Education for All Handicapped Children Act.
- The most common legal challenges that confront the citizen with the dual diagnosis are the lack of treatment services for this population and the concomitant range of excessively restrictive, and at times, punitive intervention strategies resulting from the lack of adequate and appropriate treatment and programmatic interventions.
- There exists the misuse of psychoactive medications and the systematic use of restraint and punishment in lieu of active and positive developmental intervention strategies.
- There is a need to encourage further systematic analysis of the legal status of persons with mental illness and mental retardation in whatever settings they receive services.

### **Parents and Family**

- Families with members who have both mental retardation and mental illness are often left without adequate support from either of the major service systems.
- Parents with sons and daughters having these exceptional needs require a wide range of in-home and supportive services such as parent training and respite care in order to support rather than supplant the family.
- There is a pressing need to prevent mental illness in the person with mental retardation through intervention programs with the

individual with mental retardation and his/her parents through the provision of supportive services as early in life as possible. Parent training and respite care for families were the two most cited prevention strategies at the conference.

The above-noted issues, problems and suggestions represented the highlights of the papers and discussions at the strategies conference on mental illness and mental retardation. Specific recommendations are summarized as follows:

### **Recommendations**

The conference participants and authors of the papers developed a number of recommendations related to new and improved services, more relevant and in-depth training, and more innovative basic and applied research. Conference participants concurred that past gains need to be developed if this target population is to take its rightful place in the life of the family and the community. The following recommendations were in the area called innovative services:

- To create regional acute care treatment centers for the diagnosis and treatment of complex cases of mental illness in persons with mental retardation. These centers should also have an allied research and training emphasis.
- To encourage University Affiliated Facilities in general to assume the responsibility for model program development through the establishment or the support of services such as acute care, outpatient mental health clinics, day hospitals, prevocational and vocational services, parent training, medication and monitoring, and diagnostic and treatment clarification.
- To develop easy-to-administer assessment instruments that can be used by both mental health and mental retardation professionals, especially in diagnostic areas such as schizophrenia, affective disorders and personality disorders.

The area of research stimulated the following recommendations needing immediate attention:

- To conduct research relative to similarities and differences of persons with mental retardation-mental illness as compared to populations without the mental retardation component.
- To create a national data bank on research and programmatic mechanisms so that state-of-the-art information would be readily available.

- To conduct basic research related to neurochemistry, neuro-endocrinology, and neurophysiology in order to further enhance scientific understanding and to develop new intervention strategies.
- To establish a separate governmental review mechanism for research projects focusing on the problems of mental illness in persons with mental retardation.

The area of training was cited often in the conference as a major national need and it was noted that with few exceptions, mental retardation and mental health professionals are unprepared to meet the acute and chronic needs of this special population. It was recommended that institutions of higher education focus on the following:

- To increase competencies in the diagnosis and treatment of mental illness in the individual with mental retardation through continuing education experiences as well as the use of more formal training through

fellowships, residencies, and internships.

- To integrate the specialized area of dual diagnosis in all interdisciplinary training programs in professional schools.
- To develop curricula and media packages for training purposes in this specialized area.

To summarize, the purpose of this conference was to convene a complete spectrum of disciplines and points-of-view that are currently prevalent in the United States relative to dual diagnosis. The discussions and recommendations that were developed from the deliberations should provide the needed impetus to focus attention and action to this often ignored problem.

A hardback book was published providing the full text of papers presented at the PCMR National Strategies Conference. The title and source is as follows: Jack A. Stark, et al, *Mental Retardation and Mental Health Classification, Diagnosis, Treatment, Services*. Springer-Verlag, New York (1987).

# Highlights From the National Conference on State Planning for the Prevention of Mental Retardation and Related Developmental Disabilities

## Introduction

In keeping with its executive mandate to "evaluate the status of the national effort to combat mental retardation" and to "develop and disseminate such information as will tend to reduce the incidence of mental retardation and ameliorate its effects," the President's Committee on Mental Retardation (PCMR) sponsored a National Conference on State Planning for the Prevention of Mental Retardation and Related Developmental Disabilities. The purpose of the conference was to stimulate commitment to a national effort to prevent mental retardation and related developmental disabilities. This meeting took place February 11-12, 1987, in Washington, D.C.

## Background

The PCMR has as one of its basic goals to reduce the incidence of mental retardation in the nation. The conference was designed to take stock of the current status of prevention of mental retardation in the United States and also to learn of methods and strategies to plan for the future in the area of prevention. The interest level for this important conference was high and a record number of public and private sector agencies demonstrated a strong commitment to and support of this initiative. Twelve national mental retardation constituency organizations joined the PCMR in co-sponsoring the conference. Participants included prevention planners, service providers, advocacy group representatives, educators, health officials, Federal and State government personnel and legislators.

## Paper Presentations

"As individuals involved in the field of prevention of diseases and promoting health, we must strive to work in every possible relationship together from the local level to the national scene in order to be most effective in delivering the public message to our citizens. A long chain must be formed to meet this challenge, and each one of you is a vital and very important link in that chain. The success of the strength of that chain will be limited by the well-

known adage—it is only as strong as its weakest link." This was spoken by Robert E. Windom, M.D., Assistant Secretary of Health, U. S. Department of Health and Human Services, in setting the tone and objectives for this important conference on prevention.

Duane Alexander, M.D., Director of the National Institute of Child Health and Human Development, opened his presentation with the following quote, "Nationwide thinking, nationwide planning, and nationwide action are the three great essentials to prevent nationwide crises for future generations." Dr. Alexander noted that no one knew more about nationwide crises than President Franklin D. Roosevelt. He had spoken these words more than a half a century ago, but these words apply to the participants of this conference and to the activities of the President's Committee on Mental Retardation. Dr. Alexander stressed that governments at all levels, private foundations, philanthropies, and our citizens must be convinced that efforts directed toward prevention are cheaper, more effective, and more humanitarian than efforts solely directed toward treatment or care. No one can do it alone, but there is a cooperative role for each of us and at every level from government to the private citizen.

The summaries of the papers presented for discussion at the conference are focused in three general areas. The papers include biomedical approaches, social-cultural approaches, and a view of State/Territorial findings.

## Biomedical Approaches

In his paper entitled, "Planning for Prevention of Mental Retardation," Duane Alexander, M.D., described a variety of biomedical approaches to be designed to prevent mental retardation and other developmental disabilities. He noted an early success in prevention coming as a result of the Phenylketonuria (PKU) Screening Test in the early 1960's. In the past two decades, newborn screening and diet treatment has been instituted in every State with Federal assistance. He noted, however, that we are faced with a new problem of

maternal PKU. Girls with PKU treated with diet in infancy now reach reproductive age with normal intelligence. Previously, these women were profoundly retarded and did not reproduce. However, they are now having children, and we are discovering that the high phenylalanine level of these women in pregnancy is toxic to the developing fetus. Most of their children are abnormal at birth, with microcephaly, mental retardation, and/or congenital heart disease. If each woman with PKU were to have two children, in one generation we would have the same number of persons with mental retardation as a consequence of PKU as we had before screening began. Obviously additional research is needed to prevent and/or treat this aspect of PKU, and the National Institute of Child Health and Human Development (NICHD) has launched a major PKU international collaborative study to assess whether re-institution of a low phenylalanine diet, either pre-conception or in early pregnancy, can prevent fetal complications. This is one of the broadest prevention research efforts ever mounted, involving all 50 states and all provinces of Canada, trying to identify PKU women of childbearing age and younger, provide counseling on their pregnancy risks, and enroll them in the study. Professions in the mental retardation field can help by counseling their patients with PKU and referring them to the study.

Another area where early prevention has paid off is in curtailing congenital rubella. The rubella epidemic of 1965-1966 produced 25,000 cases of the rubella syndrome which caused mental retardation, deafness, and congenital heart disease. The rubella vaccine developed in 1969 by the Public Health Service at the National Institutes of Health and the Food and Drug Administration has effected a marked decline in both rubella and the congenital rubella syndrome. Today, over 95% of children are immunized at school age with assistance from the Federal immunization program. In 1985, the Centers for Disease Control reported only two cases of congenital rubella in the entire United States.

Congenital hypothyroidism (cretinism) is another disorder that is on the way to being eliminated as a cause of mental retardation. This condition is now readily treated to prevent mental retardation from developing, but the majority of cases are not diagnosed in time. A screening test, using the same blood spot as in PKU screening, was developed with NICHD support in the late 1970's and tested in the early 1980's. Currently, screening newborns for congenital hypothyroidism is done in all States similar to PKU screening. Since this condition is four times as frequent as PKU, at least 1,000 cases per year of mental retardation are prevented.

Erythroblastosis fetalis (Rh hemolytic disease) is another disorder that causes mental retardation. This condition develops as a consequence of an Rh + baby in an Rh - mother. The mother is sensitized to the baby's

Rh + cells at delivery. In a future pregnancy, her Rh antibodies destroy her baby's red blood cells, causing anemia, jaundice and, in some cases, cerebral palsy, deafness, mental retardation, or death. In the late 1960's, researchers developed Rhogam (antibody to fetal Rh + cells) that destroys them in the mother's blood before they sensitize her. A single injection given to an Rh - mother at delivery will prevent sensitization and thus avoid complications in future pregnancies. The use of Rhogam prevents several thousand cases of mental retardation per year.

Amniocentesis used for prenatal diagnosis of genetic disease is, in part, a way to prevent mental retardation. This diagnostic technique, developed in 1968, has since become widely available. In combination with a shift away from older maternal age at childbearing and public education, amniocentesis has resulted in a 25% decrease in incidence of Down Syndrome and a comparable decrease in other cytogenetic causes of mental retardation.

The need for prevention research of a biomedical basis continues and the use of new tools of genetics, neurosciences and molecular biology offer increased hope for the prevention of mental retardation and other developmental disabilities.

### **Social-Cultural Approaches**

In a paper delivered to the conferees, Ms. Arlene Mayo indicated that mental retardation and other developmental disabilities do not discriminate on the basis of race, ethnic group or socioeconomic class and that all segments of the population may be at risk. Studies, however, indicate that the socially disadvantaged have historically been the victims of an over representation of mental retardation and related disabilities. She went on to note that the Black population showed an even larger disparity in viewing this problem. Factors that tended to influence these differences included low birthweight, access to services, poverty and other socioeconomic indicators.

Dr. Alfred A. Baumeister corroborated the above issues in his paper entitled, "Effective Planning Strategies to Prevent Mental Retardation Among Socially Disadvantaged Populations." He stated that it is well recognized that the environment in which a child grows and develops exerts a powerful force upon the intellectual, emotional, and physical development of that individual. Poverty and low socioeconomic status have been found to be a major contributing factor in higher incidences of many disabilities including mild mental retardation. He noted that research studies have shown that social, economic and cultural factors are major causes in prematurity and intrauterine growth retardation, and that these conditions in turn; increase the risk of perinatal problems and neurological disability. These adverse conditions are linked with postnatal dysfunction

including learning problems, behavioral problems, and lower intellectual functioning as measured by the I.Q.

The National Institutes of Health publication entitled, "Prenatal and Perinatal Factors Associated with Brain Disorders" (1981), listed three major ways in which these social, cultural, and economic factors contribute to brain dysfunction. These included: (1) By virtue of life circumstances, the child before or after birth may be placed in harm's way and thus have an increased exposure to high risk conditions which in turn lead with greater frequency to brain disorders; (2) A lack of timely and effective rehabilitative services may maximize central nervous system injury and compromise learning during a critical developmental period; and (3) In an unfavorable environment a child with brain injury may also develop in a maladaptive manner. Because of this double jeopardy, a child may perform worse than expected due to either brain injury or social, cultural and economic factors alone.

Dr. Baumeister pointed out that to understand the relationship between poverty and later morbidity, it is important to view poverty not as an isolated condition, but rather as an ongoing process that interacts at all levels with an individual's ability to function within a given environment. The effects of poverty begin at conception. Low birthweight is a major factor in infant mortality with these babies being 40 times more likely to die in the first four weeks of life than a normal weight infant. If they do survive, the low birthweight (LBW) infant is three times more likely to have a neurodevelopmental handicap, and this risk increases as birthweight decreases. In addition, infant mortality rates seem to have recently increased in the United States among some ethnic or racial groups. The U.S. currently lags behind 16 other nations with respect to infant mortality.

A review of the data from this paper shows that a clear pattern emerges as to those most likely to give birth to a low birthweight baby. Demographically, those at highest risk are under 17 and over 34 years of age, Black, low socioeconomic status, unmarried, and have a low level of education. Behavioral and environmental risks include smoking, poor nutritional status, substance abuse, and toxic exposures including occupational hazards. When you connect these demographic, behavioral and health variables together there is a strong correlation between them and poverty.

In 1975, Robert Haggerty and his associates introduced a phenomenon they termed the "new morbidity." The conditions associated with the "new morbidity" at that time were described as behavioral and school problems among children and adolescents. Also included were environmental risks with personal behaviors such as drug and alcohol abuse, and accidents. The model encompasses a wide array of psychological problems including violent behaviors,

suicide, mild mental retardation, adolescent pregnancy, psychiatric disorders, and chronic health problems, along with school difficulties such as emotional disturbance and learning disabilities. While none of these constitute new problems, what is more alarming about the "new morbidity" is the ever increasing prevalence of these conditions among children and adolescents throughout our society.

While the "new morbidity" affects children and adolescents from all socioeconomic levels, children who live in poverty are one and a half to two times more likely than non-poor children to suffer from disabilities. This is supported by government figures showing that for those individuals under 18 years of age experiencing limitations in major activities more than twice as many are from families earning under \$10,000 per year when compared with those from families earning \$10,000 or more per year. The same holds true for five through 17 year old persons who are rated in fair or poor health, with a sevenfold increase (in disabilities) for those individuals in the lower income group when compared with the higher income group.

In summary, the matter of serving ethnic/minority populations who are considered socially disadvantaged requires positive actions in implementing the many common-sense recommendations that have been generated from many studies. Providing culturally relevant materials, recruiting and training bilingual/bicultural service providers, and the development of culturally responsive service models must be considered in realistic prevention efforts. There are many models of prevention programs that have demonstrated that early intervention works. However, reaching the population at risk, namely the socially disadvantaged, requires one to consider their own values as they relate to the known barriers to service delivery and to draw from their own creativity to the service meaningful, available and obtainable. While we can expect the many scientific and technical advances including new tests, new drugs and new genetic engineering breakthroughs in the future, the basic solutions and interventions needed are not of a technological nature, but more of social/political orientation.

### **State and Territorial Activities**

The Conference participants discussed and exchanged numerous actions and programs taking place in the various States. For the purposes of this report, some excerpts from around the nation are described in this section.

#### **The California Experience**

In California, for example, over 450,000 people with developmental disabilities require some kind of specialized program. In fiscal year 1986-1987, the Departments

of Education and Developmental Services together will spend in excess of \$2.4 billion to provide these services. The following are some of the factors that illustrate the impact that birth defects and developmental disabilities have on all of us:

In the coming year, 25,000 infants, because of prematurity or birth defects, will be admitted to Neonatal Intensive Care Units at a cost of over six hundred million dollars. A State-wide prevention program of education, counseling, and expanded perinatal care can reduce this cost by one-third.

Almost 9,000 Neonatal Intensive Care Units infants will be rehospitalized during their first year at a cost of fifty million dollars. Twenty to fifty percent of these rehospitalizations will result from child abuse and neglect. One-half of these cases can be prevented by providing high-risk infant follow-up programs, including home services and parental counseling.

A document entitled, "Prevention 1990: California's Future:" presents, for the first time in California, a coordinated State-wide plan to address these problems and to reduce the incidence and severity of birth defects and developmental disabilities. It was noted that the experiences gained from prevention efforts in California, the United States, and from other countries documented that the costs for prevention efforts are returned or "paid back" many times over. These benefits are associated with reduced human suffering, increased individual potential, and the substantial savings in treatment and long-term care services.

The California Task Force and the Office of Prevention identified eight essential services which must be addressed if the incidence of developmental disabilities is to be reduced, and these include the following:

- Perinatal Care.
- Early Intervention Services.
- Genetic Services.
- Environmental Hazards.
- Prevention Education.
- Public and Professional Education.
- Management Information Systems.
- Administration. (This is to insure that the recommendations contained in the plan are carried out in a timely and cost-efficient manner.)

The California Plan described briefly, identified prevention goals and objectives which constituted a coordinated "blueprint" for action to be implemented within the next five years.

#### **The Ohio Prevention Project**

In 1980, the Ohio Developmental Disabilities

Planning Council, an arm of the Ohio Mental Retardation/Developmental Disabilities (MR/DD) Department, undertook to do something tangible in the way of prevention. It incorporated the concept of *prevention* into its State Plan, with the following goals: 1) to lower the incidence of developmental disabilities through better utilization of existing services and knowledge; and 2) to ameliorate the effects of developmental disabilities by ensuring that all children in Ohio have access to early identification and appropriate intervention services as needed.

In order to effectively address these goals, the importance of training for professionals, general consumers, and teenagers to establish a comprehensive prevention strategy was recognized. From these beginnings, the State-wide DD prevention continuing education project was conceptualized in October 1983. Funded by the Ohio Department of MR/DD, this program is complementary to the prevention goals and objectives outlined in the Ohio DD Planning Council's State Plan and is expected to continue through December 1989. The Ohio Prevention Continuing Education Project has developed an interagency training model with the potential for out-of-state replication. It should be noted that the model exemplifies interagency collaboration and builds upon the effective use of existing resources.

The major collaborative partners in the project are Ohio's two University Affiliated Facilities (UAF), the Ohio Area Health Education Centers (AHEC), and the Ohio Cooperative Extension Service (OCES). In addition, secondary schools have been incorporated as a vital component of Ohio's State-wide DD prevention training network.

Extensive project materials were developed and field-tested for use with physicians and nurses, allied health professionals, general consumers, and, of course, teenagers. In general, the materials addressed prevention strategies that are associated with four major time periods and include 1) Preconceptual, 2) Prenatal, 3) Birth, and 4) Postnatal. A broad array of training models and other materials have been developed for various audiences and provide a wide variety of prevention information.

In summarizing the Ohio experience, it was stressed that each State must identify existing resources that provide professional and consumer education and creatively unite and motivate these resources to establish a comprehensive, collaborative venture in training and awareness in prevention of developmental disabilities. The UAF's are in an excellent position to serve as the catalyst for this kind of State-wide DD prevention training effort.

## The New Jersey Public-Private Initiative

In 1984, with the support of key government officials, at the request of the Director of the Division of Developmental Disabilities, the Commissioner of Human Services convinced the Governor of New Jersey to adopt the prevention of mental retardation as an important new policy area by emphasizing both the cost-effectiveness and humaneness of this approach. The Governor took the occasion of his annual message to the New Jersey State Legislature in January of 1984 to announce the creation of an Advisory Council on Prevention of Mental Retardation, with the mission of developing a Statewide plan for prevention. Support for the policy was enhanced by the involvement of the State's First Lady who played a significant role in focusing attention on the problem of mental retardation and the need for improved prevention strategies.

The Governor's Executive Order which established the Council, set out the task of designing services and mobilizing support for prevention in six points. In order to design services, the Council was directed to do the following:

To study the prevention of mental retardation and develop a comprehensive plan.

To evaluate prevention activities in New Jersey and in other States.

To develop mechanisms to facilitate detection of the causes of mental retardation.

In order to mobilize support for prevention, the Council was directed:

To mobilize citizens and community agencies in a strong effort for prevention.

To foster cooperative working relationships among the relevant agencies.

To define and convey to the public information about the prevention of mental retardation.

The prevention Council was composed of a truly representative body from State government, social service organizations, business, and industry. These members were linked with parents of citizens with mental retardation, making it possible for the public and private sectors to plan together effectively.

The past few years have generated several prevention projects of note, such as the following:

A prevention program resource manual presented in a format appropriate for students and adults in the community.

An emphasis on prevention in curricular and professional publications in medical schools and professional associations.

A project to provide to every health or family life education teacher in the State a prevention kit which included information on the causes of developmental disabilities such as use of drugs, alcohol, tobacco, poor nutrition, lack of seat belt use, lead poisoning, and adolescent pregnancy, and materials that can be used with students to create an awareness that can have significant impact on reducing the incidence of mental retardation and related development disabilities. Along with the kits, inservice training for the teachers will be provided.

These are just a few of the ways that the State of New Jersey has approached the challenge of prevention activities which has sparked enthusiasm from the Governor's office to the local community.

While we are limited in the size of this report, other States that described their programs at the Conference with written reports included Indiana, New York, North Carolina, and Virginia.

## Recommendations

In February 1987, the President's Committee on Mental Retardation (PCMR), along with co-sponsors from other Federal agencies, private advocacy, and professional organizations convened a major national conference to stimulate and facilitate planning for the prevention of mental retardation by States and Territories. This report emphasized the broad-based approach that is needed to deal with the issue of prevention. The deliberations focused on the biomedical and socio-cultural approaches to prevention. In addition, papers were delivered by representatives of many States where innovative projects are underway. Major recommendations are summarized as follows:

- *Public awareness*—The media and its messages during pregnancy, early childhood, abuse, and the like, greatly influence lifestyles of the socially disadvantaged. Reaching out to pockets of socially disadvantaged, they often promote messages that encourage unfavorable lifestyles during pregnancy. The media must be encouraged to be more responsible as they impact on this population.
- *Outreach*—It is a sad fact that many socially disadvantaged persons tend to be unserved due to a number of factors that impede their ability to access services that are available. Approaches need to be developed to correct this problem.

- *Holistic Approach*—We must consider the needs of the entire family and the identified person as a member of the system; only then can we prevent reoccurrence. The family system has become fragmented, however, studies indicate that they still influence the approach to service systems.
- *Training Opportunities*—More opportunities for the minority population must be available so that they can be provided services within their own community. The recruitment of minority service providers to the field of developmental disabilities and mental retardation is critical when the numbers of socially disadvantaged within the population is considered. The issue may not be merely the need to match ethnicities, i.e., black worker, black client, but to have workers who approach clients with genuine respect and an understanding and acceptance of the client's culturally relevant needs.
- *Making Prevention a Priority*—It has been clearly documented that 80% of all developmental disabilities and mental retardation could have been prevented. Therefore, consideration must be given to the priorities of early prenatal care, optimum quality of care, early intervention program, to name a few.
- *Legislation*—Laws are needed to ensure access to prenatal care for all women, with special emphasis on reaching the medically and/or socially disadvantaged high-risk mothers for services. Special attention must be given to pregnant, developmentally disabled women who opt to become parents.
- *Prevention Research*—The need for prevention research of a biomedical basis continues, and the use of the new tools of technology in the area of genetics, the neurosciences, and molecular biology should press forward in the realm of prevention.
- In order to reach the Presidential goal to reduce the incidence of mental retardation by 50% by the year 2000 A.D., the resources of the governmental and private sectors must be mobilized. This will require total coordination of efforts at every level of government in concert with professional and advocacy groups.