Report
to the
President

1993-2003

1993
The National Effort to Prevent Mental Retardation and Related Developmental Disabilities

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TOPIC

PREFACE

The President's Committee on Mental Retardation was established by Executive Order 11280 on May 11, 1966, to provide continuing advice and assistance to the President and to the Secretary of the Department of Health and Human Services on all matters pertaining to mental retardation. The Committee is comprised of the Secretary of Health and Human Services, who serves as Chairperson, the Attorney General of the United States, the Secretary of Education, the Secretary of Labor, the Secretary of Housing and Urban Development, the Secretary of Transportation, the Director of ACTION, and 21 citizen members appointed by the President.

The Executive Order of May 11, 1966 establishing the President's Committee on Mental Retardation directs the Committee to submit "such reports or recommendations to the President concerning mental retardation as he may require or the Committee may deem appropriate. Such reports shall be made at least once annually." The Annual Reports have helped the Committee fulfill its mandated function to "develop and disseminate such information as will tend to reduce the incidence of mental retardation and ameliorate its effects."

Consequently, this report entitled Report to the President: The National Effort to Prevent Mental Retardation and Related Developmental Disabilities is a direct outgrowth of the Committee's activities as specified in the Presidential order and the Charter. It is also the result of continuing interest and efforts of Committee members and staff who have been active participants on the PCMR Prevention Subcommittee.

The President's Committee on Mental Retardation has provided leadership in the national effort to minimize the occurrence of mental retardation. The Committee convened in February, 1987, the first National Conference on State Planning for the Prevention of Mental Retardation and Related Developmental Disabilities. Subsequent to the Conference, PCMR developed and widely disseminated a Guide to State Planning for the Prevention of Mental Retardation and Related Disabilities and a companion document, Preventing the New Morbidity: A Guide for State Planning for the Prevention of Mental Retardation and Related Disabilities Associated with Socioeconomic Conditions. The Committee has also catalyzed Federal, State and local efforts to prevent and ameliorate the effects of mental retardation. Two PCMR-sponsored national conferences within a four-year period called attention to the urgent need for State and territorial planning to prevent mental retardation and related disabilities.

PREFACE - (Con't)

The February, 1987 National Conference on State Planning stimulated commitment to a national effort to prevent mental retardation and related disabilities. The two hundred fifty conference participants included prevention planners, service providers, advocacy group representatives, educators, researchers, health officials, legislators, and Federal and State government officials who came from 33 States, 3 territories and the District of Columbia. They represented prevention programs based in urban and suburban communities, and in rural counties and townships. The State and territorial participants deliberated and were provided technical assistance intended to facilitate their success in conceptualizing, planning, implementing, and/or enhancing State plans for the prevention of mental retardation.

The February, 1991 PCMR-sponsored Summit on the National Effort to Prevent Mental Retardation and Related Disabilities addressed the adequacy of the national effort to prevent mental retardation and related disabilities, and charted the course for future strategies to reduce the incidence and ameliorate the effects of these disabilities, particularly when caused by socioeconomic conditions. This international, interdisciplinary meeting included heads of Federal agencies, representatives of Governors, offices and Developmental Disabilities Planning Councils, health officials, prevention planners, service providers, consumer advocates, educators, researchers, and legislators. The conference participants came from thirty of the continental United States, the District of Columbia, South Africa, Saipan and Mariana Islands. The Summit facilitated interdisciplinary efforts of professionals and constituency groups to contribute to the development of a comprehensive national plan to reduce incidence rates in mental retardation and related disabilities by improving options for mothers, infants, and children. This working Summit featured technical presentations by renowned leaders in the field; stimulating work group sessions that addressed key issues that impact prevention initiatives at the national, regional, State and community levels; discussion by agency executives of interagency approaches and options to prevent disability; and practical recommendations believed to be both realistic and achievable.

The technical papers, deliberations, recommendations and other relevant proceedings of the 1991 Summit on the National Effort to Prevent Mental Retardation and Related Disabilities comprise the basic content of this Annual Report.

ACKNOWLEDGEMENTS

Members and staff of the President's Committee on Mental Retardation acknowledge the leadership and support of Dr. Albert L. Anderson, Committee Vice Chairperson, and Dr. William Kerby Hummer, former Chairperson of the PCMR Prevention Subcommittee, in convening the Summit on the National Effort to Prevent Mental Retardation and Related Disabilities.

The Committee also wishes to give special acknowledgement to the National Coalition on Prevention of Mental Retardation for providing consultation, fiscal and personnel support during the planning of the Summit, and invaluable assistance during the implementation of the conference.

The PCMR recognizes the contributions made by participants in the 1991 Summit on the National Effort to Prevent Mental Retardation to the success of the Summit. The speakers, exhibitors, work group leaders, facilitators and recorders, and many of the audience participants are nationally renown leaders in the field of mental retardation, prevention, pediatrics, and early childhood development. The expert presenters of technical papers made particular contributions to the development of this Annual Report by providing updated information reflecting the current status of the national effort to prevent mental retardation and related disabilities.

The President's Committee on Mental Retardation recognizes with special appreciation the fiscal and personnel support provided by the following public and private sector agencies in co-sponsoring the Summit proceedings that form the basis of this report:

> The American Academy of Pediatrics (AAP);
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> The National Institute of Disability and Rehabilitation Research, U.S. Department of Education; and
>
> The U.S. Department of Health and Human Services Administration for Children, Youth, and Families (ACYF); Administration on Developmental Disabilities (ADD); Administrat-ion on Aging (AoA); Centers for Disease Control (CDC), Division of Birth Defects and Developmental Disabilities; National Institute of Child Health and Human Development (NICHD); Office of Disease Prevention and Health Promotion (ODPHP);
>
> Office of Policy, Planning and Legislation (OPPL) now known as the office of Policy and Evaluation (OPE); and Social Security Administration (SSA).

Finally, the PCMR acknowledges the contributions of former and current Committee members, especially members of the Prevention Subcommittee, who worked to facilitate the success of the Summit. The PCMR also recognizes the support of the dedicated staff for the proficiency, efficiency and cooperative spirit with which they assumed responsibilities necessary for successful implementation of the Summit. Special note is taken of the support given by Susan Gleeson, R.N., and Sambhu N. Banik, Ph.D., former Executive Directors of the PCMR.

EXECUTIVE SUMMARY

The President's Committee on Mental Retardation (PCMR) Conference in February, 1991, "Summit on the National Effort to Prevent Mental Retardation and Related Disabilities," was the programmatic highlight of the Committee's 25th Anniversary in 1991. The selection of the topic of prevention for this jubilee event was exceedingly fitting, inasmuch as the PCMR has through this quarter century been a continuing voice for the potential of prevention and its humanistic implications. The Committee has been unique in its devotion to bringing together the nation's diverse agencies, centers, and spokespersons concerned with prevention of mental retardation and developmental disabilities.

Ten plenary speakers on the topical aspects of prevention provided a richness of experience and commitment. For the purposes of this Annual Report, material has been excerpted from their presentations dealing specifically with aspirations for the future of the field. Taken in the sum these notes offer substantial hope, while also speaking of a requirement for enhanced resolve. When added to the recommendations developed by the conference work groups it becomes clear that there is much to be done.

Duane Alexander, in his Keynote Address, looked positively at recent research, and expressed anticipation for applications of gene therapy, fetal therapy, and potentiation of regeneration within the central nervous system. Hugo Moser, in the Statement of Occasion, stressed the need for greater accuracy in diagnosis of the origins of mental retardation, for appropriate use of the Deoxyribose nucleic acid (DNA) studies, and for a search for the biologic basis of learning disabilities. Godfrey Oakley presented a concept of "prevention epidemiology," and recommended a network of epidemiology centers with this orientation. The effort to produce the encompassing objectives of "Healthy People 2000" was described by Ashley Files, noting their particular orientation to decreasing the outcome disparities in many health areas now experienced by minority citizens. Allen Crocker reviewed the ambitious recommendations brought forward by the Institute of Medicine's "National Agenda for Prevention, " and expressed the belief that workers involved with mental retardation could find the right plans there.

Alfred Baumeister recounted his comprehensive conception of the "New Morbidity" and its threats to young persons. As he states, "Politics, poverty, and disadvantage have extracted a terrible toll on our children. " Edward Zigler summarized our need for creative early education for children at risk. The challenge represented by "chemically dependent families" was addressed by Judy Howard, who felt that effective corrective services can be designed. Herbert Cohen spoke of the multifactorial needs of children with congenital Human Immunodeficiency Virus (HIV) infection, and the personnel training requirements to provide for them. Travis Thompson reminded us that "Tackling problems associated with poverty is not a challenge for the faint of heart. The time is overdue that we stop shrinking from our responsibilities."

The breadth of Federal involvement in prevention activities was presented by the leaders of nine agencies. Services for women and children, Head Start, family assistance, and early childhood education were among the many areas reported.

The conferees divided into five work groups to reflect on the material offered. They produced a list of 25 recommendations, dealing with research requirements (for improvement of the knowledge base), basic supports for all families (to assure egalitarian access for life needs), and improved planning for prevention (for thoughtful mobilization of resources). The conference recommendations address the need for research in etiology and epidemiology, mandatory curricula in preparation for parenthood, "consumer-friendly" services to remove barriers, assistance in employment, housing, and environment, and universal health insurance. They also seek more consumer based planning and meaningful interagency alliances.

The President's Committee invited four States to present illustrations of exemplary programs in prevention. These programs involved outreach childbirth education (Florida), prevention of adolescent and unwanted pregnancy (Iowa), prevention of lead poisoning (New Jersey), and enhancement of public awareness (California).

As an epilogue some notes are offered on the adequacy of our current national effort on prevention of mental retardation and developmental disabilities. In this regard, kudos are given for many important successes regarding disability of biomedical origin, but alarm expressed that new liabilities appear to be mounting, relating especially to the role of social disadvantage. Many indicators of child health and developmental potential are not improving, including low birthweight rates, the racial disparity in infant mortality rates, teenage fertility rates, substance abuse in pregnancy, birth incidence of HIV infection, and reports of child abuse. Conferees expressed appreciation for the Disability Prevention Program of the Centers for Disease Control (CDC), now known as the Centers for Disease Control and Prevention (CDC), which has already provided aid to 28 States. It is clear, however, that a larger national commitment is needed, with special emphasis on creative social programs.

THE FUTURE

In reviewing the materials and discussions of the 1991 25th Anniversary conference, the "Summit on the National Effort," it seems especially appropriate for the President's Committee on Mental Retardation to seek out the vision of the future as revealed during that landmark PCMR occasion. The speakers had much to say about the future, with particular ideas on scientific research, data collection, planning for vulnerable populations, public program administration, priority setting, and new considerations for very young children, social reform, and personnel preparation. These recent ideas of theirs remain very cogent; direct excerpts will be given from the Proceedings, so that the Conference faculty can indeed "tell it in their own words." And then the future Recommendations of the Work Groups will be looked at again, where many of the assertions appear in more operational format.

In his Keynote Address, Duane Alexander, Director of the National Institute of Child Health and Human Development, spoke of achievements in prevention of mental retardation of biomedical origin, in the areas of Phenylketonuria (PKU), congenital hypothyroidism, Rh disease, measles encephalitis, and rubella encephalopathy. The importance of new diagnostic understanding was mentioned (such as Rett syndrome and urea cycle disorders), and current work was reported on Hemophilus influenza vaccine, medications to reduce the effects of hyperbilirubinemia and of cerebral anoxia, new understanding of the cytogenetics of Down Syndrome, and dietary intervention for adrenoleukodystrophy was reported.

What about future directions in mental retardation-developmental disabilities (MRDD) research? Talking about this is very risky, because science is moving so fast that what you call the future often turns out to have been done yesterday.

Gene Therapy *A case in point, and one of the most exciting frontiers ever in medicine, is gene replacement therapy. The future is here, and you in the field of MRDD have the good fortune to be right in the middle of it. On Thursday, September 14, 1990, at the National Institutes of Health (NIH) Clinical Center in Bethesda, a 4-year-old girl with Severe Combined Immune Deficiency (SCID) became the world's first patient to have her disorder treated with gene replacement. Doctors earlier had removed some of her blood, separated out the white blood cells, and used a virus vector to carry into those cells the gene for making the enzyme adenosine deaminase (ADA) that she was born without. 7he gene entered the Deoxyribose nucleic acid (DNA) of some of those cells and started producing ADA. Last September 14 those cells were injected into the patient, and she will be monitored to see how well these cells continue to produce ADA. A total of 10 children will be included in this protocol, the most extensively and critically reviewed clinical study ever undertaken. We should know in a few months if it is working, but there is little doubt that it will. It is not often you can talk about a new era in medicine, but this truly is one of the greatest steps forward in the history of humankind we can do it for SCID, we can do it for Lesch-Nyhan, Tay-Sachs, or any other genetic disorder for which we identify and clone the gene and provide correction before irreparable damage occurs. Many of the hundreds of genetic causes of MRDD where we have had nothing to offer before, will become amenable to treatment by this approach and the modifications of it that will surely come.*

Fetal They. Another new frontier is fetal therapy, first begun in the 1960's by Liley with intrauterine transfusion for Rh disease, and most recently crossed by Mike Harrison and Mickey Bolbus with actual fetal surgery, in which the fetus is removed from the uterus, a congenital anomaly such as obstruction of the urinary tract or diaphragmatic hernia is corrected, and the fetus is returned to the uterus for the pregnancy to continue. These are heroic procedures, but there are other variants of fetal therapy that are coming that mean that we will at last have something to offer after fetal diagnosis other than genetic counseling and the option of pregnancy termination for fetal defect. At the recent Congress of the Transplantation Society, physicians from France reported success in treating fetuses with immune deficiency or thalassemia by injecting liver cells from aborted fetuses into the fetuses with the genetic defects. Although these studies will have to be replicated and confirmed, it is likely that this will be an effective means of fetal therapy for some genetic disorders. Another approach to fetal therapy is still in the animal study phase, and involves prenatal surgery to correct neural tube defects such as spina bfida or meningomyelocele to prevent paralysis. Neurologist John Freeman and neurosurgeon Dan Hafez postulated that the permanent neurologic damage from this lesion might be due to exposure of the bare spinal cord and nerves to toxic substances in amniotic fluid, and if the lesion were closed before the damage occurred, paralysis might be avoided. Working with a mouse model, Hafez has demonstrated that early closure of the meningomyelocele in the fetus eliminates postnatal neurologic deficits. If this holds with other animals and carries over to humans, our screening of pregnancies with serum AFP and ultrasound for neural tube defects may result in the ability to correct the lesion prenatally and prevent neurologic complications.

Neurobiology. The 1990's have been declared the "Decade of the Brain' by Congress and Presidential proclamation, and neurobiology represents another exciting frontier for the MRDD field. Discoveries relating to the programmed development of the Central Nervous System (CNS), abnormalities in nerve cell migration that could account for some forms of mental retardation, and discoveries that nerve cells can in fact regenerate in the brain and spinal cord, offer whole new fields for study and potential therapeutic application to mental retardation, spinal cord injury, cerebral palsy, and learning disabilities. This is one of the hottest and most exciting areas in all of medicine and biology, and once again you in the MRDD field are tight in the middle of it.

New Hazards and Challenges. Just when we seem to make progress against one disorder, another often appears to take its place. We eliminated PKU only to create maternal PKU. We are eliminating H.flu meningitis, but it appears its case numbers will be more than made up for by patients with congenital Acquired Immune Deficiency Syndrome (AIDS). As if that were not enough, the national cocaine epidemic promises to flood the MRDD field with "crack babies " showing signs and symptoms of brain damage due to their mothers' use of cocaine during pregnancy. Finding ways to manage the irritability, learning problems, and antisocial behavior of these children will challenge a whole generation of MRDD personnel. Add to that an increasing number of ever-smaller low birth weight babies who survive but with some neurologic impairment, and increasing number of babies born to unmarried teenage mothers and thus high-risk by definition, and rising rates of babies with congenital syphilis who are slipping through our screens, and you have an unending source of patients and topics for the MRDD research agenda as it addresses the new morbidity.

Hugo Moser, Director of the Center for Research on Mental Retardation and Related Aspects of Human Development, at the Kennedy Krieger Institute, Johns Hopkins University, offered some similar predictions as part of his opening Statement of Occasion.

Finally, I want to highlight some of the advances that I think can happen during the next decade. I would like to make a plea for precision of diagnosis. We now know that there are more than 1,000 separate causes for mental retardation. We need to insist on the same degree of diagnostic accuracy as we now take for granted, say, in heart or kidney disease. Nobody would accept nowadays the statement that the patient has a "heart problem but we don't really know why and what does it matter anyway. " Yet for mental retardation, this attitude still flourishes. I believe the point has come that we can take an active stance and insist on correct diagnosis, both because of the practical implications and because of the symbolism that we leave behind the therapeutic nihilism which has too much applied to this field.

Secondly, I believe that during the next decade or perhaps a bit longer, all of the major causes of genetically determined mental retardation will be identifiable at the gene level with deoxyribose nucleic acid (DNA) studies. The implications of this are very hard to come to grips with. It will introduce an entirely new approach in respect to diagnosis and prevention. Gene therapy will become possible for some of the genetic causes of mental retardation.

Another area that I am very excited about is that there are efforts which I believe will be successful to reduce the devastating effects of brain oxygen deprivation. At present, four minutes of oxygen deprivation to the brain leads to irremediable damage. If this can be ameliorated, the benefits in respect to perinatal damage and the effects of drowning would be incalculable.

Lastly, I believe it will become possible to understand the biological basis of learning disabilities. In the field of vision, that has been determined, but I believe that the environmental, biological interactions which, if you will, are the basis of the New Morbidity, will become decipherable and that will have major effects on our ability to prevent and treat mental retardation.

Godfrey Oakley, Director of the Division of Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, in Atlanta, spoke of the need to bring quantitative methods to the study of mental retardation. He has provided definitive leadership in the development of the field of "prevention epidemiology," defined as "the maintenance of a scorecard to monitor the progress of prevention efforts, etiologic research to identify leads for future interventions, and prevention effectiveness research to ensure that proposed interventions are truly effective. " For the future he urges a more systematic approach for data collection, study, consultation, and training.

We believe that a network of prevention epidemiology centers--a structured Federally-supported program in which epidemiologic researchers can address scientific issues of importance to State and community prevention programs. This group would do the following:

a. Develop common approaches to data collection and analysis that permit the monitoring of regional and temporal trends in the prevalence of critical childhood disabilities.

b. Advise and consult with State- and community-based programs in the interpretation of the current science base.

c. Develop epidemiologic methods for use by State- and community-based prevention programs in improving efficacy and accountability.

d. Conduct etiologic and prevention-effective research that have national significance.

e. Provide epidemiologic training for personnel in State prevention programs.

The network of prevention epidemiologic centers must establish programs with the critical mass to serve as a regional and national resource. We should start with existing programs that have already developed such a strong base of epidemiologic expertise and add others as resources permit. Additional Federal funding should supplement the primary support obtained from other sources. Participants in the network should also have access to rich data bases that could be used to address important questions in prevention epidemiology.

Ashley Files, a Prevention Policy Advisor at the Federal Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, made major contributions to development of the Healthy People 2000 objectives. She described the methods for achievement of public and agency consensus as the objectives were framed. Three summary goals were formulated; two of them speak to critical issues in the outlook for prevention efforts: "To reduce health disparities among Americans," and "To achieve access to preventive services for all Americans."

Each of these goals is supported by the 300 specific objectives continued in Healthy People 2000 but probably none is so well supported as the disparity goal. In addition to the objectives, Healthy People 2000 includes just over 300 "special population targets. " These targets were made part of the objectives whenever an identifiable gap between the total population and a particular subgroup could be identified. For example, there are about 60 special population targets for blacks (in such areas as coronary heart disease and infant mortality), 30for Hispanics (in such areas as diabetes and health services receipt), and 25 for people with low incomes (in such areas as high quality preschool and lead poisoning). These targets highlight the necessity of targeting programs to people in the greatest need. Further, as progress toward the objectives is tracked over the decade, the special population targets will keep the issue of disparity before the Secretary of Health and Human Services, the Assistant Secretary for Health, our Public Health Services (PHS) Agency Heads, Congress, and advocacy groups. Taken together, the goals of Healthy People 2000 assert that it is not sufficient to improve the "average health" of Americans. Real progress must be measured by assessing the health status of all groups within society and leaving no group out of that progress.

My earlier points about the process we used to set the objectives, the overarching goal of reducing disparities, are particularly relevant for reducing the "New Morbidity. " First, the New Morbidity is not entirely a health care treatment problem. Socioeconomic variables play an important, if not determining, role. As a result, you will need to broaden your scope of partners beyond those who provide and study health care. Second, as you come together to form plans of attack on the New Morbidity, there will be countless disagreements in how your goals should be accomplished. The methods we used with Healthy People 2000 to address precisely these issues, could be invaluable in achieving consensus in State planning.

> *In closing, I can only encourage you to make use of the strong points of Healthy People 2000 Reach out to all those groups and organizations that are often excluded from health planning and health solutions. Invite employers, school administrators and teachers, social workers, mayors, and recreation groups to play an active part. This is simple advice. I merely suggest that you avoid just talking to yourselves.*

An exercise in future planning was undertaken by the Institute of Medicine (National Academy of Sciences) in the work, "Disability in America: Toward a National Agenda for Prevention." This project was described by Allen Crocker, Director of the Developmental Evaluation Center at the Children's Hospital in Boston. The Institute's book-length report lists 27 Recommendations:

ORGANIZATION AND COORDINATION

1. *Develop leadership of the National Disability Prevention Program at the CDC*
2. *Develop an enhanced role for the private sector*
3. *Establish a national advisory committee*
4. *Establish a Federal interagency council*
5. *Critically assess progress periodically*

SURVEILLANCE

6. *Develop a conceptual framework and standard measures of disability*
7. *Develop a national disability surveillance system*
8. *Revise the National Health Interview Survey*
9. *Conduct a comprehensive longitudinal survey of disability*
10. *Develop disability indexes*

RESEARCH

11. *Develop a comprehensive research program*
12. *Emphasize longitudinal research*
13. *Conduct research on socioeconomic and psychosocial disadvantage*
14. *Expand research on preventive and therapeutic interventions*
15. *Upgrade training for research on disability prevention*

ACCESS TO CARE AND PREVENTIVE SERVICES

16. Provide comprehensive health services to all mothers and children
17. Develop new health service delivery strategies for persons with J, disabilities
18. Develop new health promotion models for persons with disabilities
19. Foster local capacity building and demonstration projects
20. Continue effective prevention programs
21. Provide comprehensive vocational services
22. Provide effective family planning and prenatal services

PROFESSIONAL AND PUBLIC EDUCATION

23. Upgrade medical education and training of physicians
24. Upgrade the training of allied professionals
25. Establish a program of grants for education and training
26 Provide more public education on the prevention of disability
27 Provide more training opportunities for family members and personal attendants of people with disabling conditions

The working committee that produced these recommendations considered the issues of disability in a generic sense, including, developmental disabilities, concerns surrounding injury (at all ages), chronic disease and aging, and secondary conditions. Dr. Crocker analyzed the applicability of the Agenda to persons involved specifically with mental retardation and developmental disorders, and concluded that the value was high.

First of all, the report appropriately endorses the major contributions of the Centers for Disease Control, past, present, and continuing. Their capacity building programs in the States are a courageous and significant outreach to citizens and communities to become active in a systematic way. I believe they have been of seminal importance and will continue to be. So therefore, those of us with an identification with developmental disabilities have watched with considerable gratification as these activities have addressed concerns regarding developmental disabilities in those States.

Secondly, there will be a long-overdue Federal Interagency Council. 7houghtful people have had much dismay regarding the incomplete capacity of Federal agencies to talk amongst themselves in a systematic and monitored way about their prevention plans. I remember when the PCMR attempted, about five years ago, to make a list of Federal offices that had something important to do in the prevention of developmental disabilities, and the list ran to 35 or 40 agencies. They have never been able to get together effectively. This is at long last a start. We will watch with great interest as these folks put their cards on the table. 7here would be a national advisory committee with strong consumer representation parallel to it and a voice that will be well heard, and this would also be a significant gain. And lastly, there is a requirement for monitoring and *reporting the progress of the prevention activities on a national level which has never heretofore been suggested. It is my sincere hope that this will indeed be retained.*

The need for improvement in the knowledge base is obvious; particularly in the most sensitive areas of the measurement of risks, the nature of courses, and the effectiveness of interventions.

It is gratifying that there has been in the next to last group of recommendations a proud public affirmation of the need for comprehensive services for mothers and children, for those at risk in general, and for the procurement of technology. The attention to quality of life considerations is welcome. These are all words that we use in our own meetings, and to have them presented here, in a form that can be widely circulated and become part of the national conviction, is of great value to me.

It is an important emphasis, in the IOM report, that there will be enhancement of related educational activities, particularly the training of families. It is good that there is endorsement of ongoing effective programs with no attempt to sidestep or minimize the quality of work already underway. And finally, I personally am very grateful that there has been throughout all this work, a much more thoughtful model of the disabling process and an insistence upon a humanistic vocabulary.

In other words, if you ask whether or not the Institute of Medicine report provided for us in mental retardation and developmental disabilities a critically valuable tool, the answer is yes, and for the following reasons: we do believe in the <u>CDCs importance</u>; that <u>national bodies should take some responsibility</u>; that the <u>knowledge base requires improvement</u>; that the <u>comprehensive services are a necessary reinforcement of the whole business</u>; that <u>educational activities are a necessary reinforcement of the whole business</u>; and that it is appropriate that it be looked at from a consumer's point-of-view and with <u>thoughtfulness in our vocabulary.</u>

Alfred Baumeister, Director of the Research Program on Retarded Intellectual Development, at the Kennedy Center for Research on Education and Human Development, Vanderbilt University, has in recent years provided a scholarly conception of the "New Morbidity." This speaks to the complex of interacting biomedical, environmental, and social factors that can lead to significant developmental compromise for young children, with special reference to increasingly prevalent contemporary psychosocial and health problems. Poverty and social disadvantage are critical catalytic variables. He describes the requirement in the future for enhanced commitment.

Evidence is overwhelming that recent trends affecting the health of children are not conducive to development, including such diverse public health aspects as prenatal care, low birth weight, immunizations, infectious diseases, abuse and neglect, violent behavior, and accidents. Poverty is not good for children. These facts do not seem to drive contemporary policy. The question is, then what does?

Politics, poverty, and disadvantage have extracted a terrible toll on our children. Problems associated with the new morbidity are complex, profound, and frequently irreversible *in their effects on individuals, families, and society. The human and economic costs of allowing these influences to remain unresolved far outweigh the costs of investing time and resources in research) treatment, and prevention. As society becomes more complex and pressured and as greater numbers of individuals and families find themselves facing economic, social, and environmental travail, more and more children will become the victims of psychosocial, developmental, and behavioral problems. The ever-progressing incidence of new morbidities will undoubtedly necessitate a strong national and local commitment to more preventive health care services, social services, and educational awareness programs. Terribly sensitive but diverse issues such as income distribution, screening for diseases, improved housing, health insurance, and quality day care will have to be addressed fearlessly and equitably.*

While there are some localities in the United States which facilitate routine preventive care, the fact is that we do not have a comprehensive, integrated national health policy especially for children. This is all the more dismaying because we do possess the knowledge base with which to implement cost-effective public health and educational programs. But we do not have in place the effective integrated systems to ensure continuity of programs and accessibility to services. Rhetoric alone will not solve these problems. There is light at the end of the tunnel, but it remains dim.

Solutions to the myriad problems that give rise to the new morbidity do not come easily. Indeed, the Gordian Knot of social, economic, medical, and psychological factors that produce children at risk has turned the talents of many of the very people who might disentangle it toward other more immediately solvable problems. In many instances, programs have been instituted that, like the babies they were intended to serve, failed to thrive.

As a nation we may be lured into the pretense that the poor, disadvantaged, and disenfranchised are condemned to an intergenerational cycle of despair and deprivation; that they are somehow committed to a fate of their own, one disconnected from ours. Should we let poor children suffer and die because they are a draining surplus on our society? That conclusion may make for good arithmetic, but terrible morality. Our contemporary, perfunctory, and dispirited treatment of many poor children does not enlighten our consciousness nor amplify their cries of anguish and despair. To ignore these families as the inevitable consequence of human variability is an illusion that is morally and socially harmful and wrong. This is an injustice that cannot be contained within the walls of conventional social practice. To adopt philosophies and policies that separate them from us is an injustice that reflects on our values and social order. We race toward a moral crossroad, because if the children do not have us, what hope have they?

I'll conclude with a quote from Hubert Humphrey: "The measure of a Nation is how it treats people in the twilight of life, people in the dawn of life, and people in the shadows of life. "

Edward Zigler, Sterling Professor of Psychology at Yale University, captures the excitement in the projects to bring dedicated special supports and training to disadvantaged young children and their families, with the goal of preventing the occurrence of mental retardation. He traces the improved outcomes achieved in the Milwaukee project, Abecedarian project, High/Scope project, the Yale Child Welfare Research Program, the Houston Parent-

Child Development Center, the Child and Family Resource Program and the Parents as Teachers program in Missouri. It appears clear that systematic work of this sort will be essential to achieve future goals.

Therefore it seems very clear that the most effective strategies to prevent low-level functioning among poor children are through family support. Since not all families face the same difficulties, they will not need the same types of support. Some may need little more than childcare services so they can maintain a decent standard of living. Others may need to be taught baby care and practical information about how children grow and learn. Some will need homes, jobs, and medical services. It is likely that many families will need some combination of supports rather than one, such as preschool for their children. And some will require services only until they can get on their feet, while others will need continuous assistance in one form or another over time.

A national effort to serve young, at-risk children and to ease the problems of their families comes from the amendments to the Education of the Handicapped Act Amendments of 1986, Public Law 99-457 The law is being phased in to provide coordinated services to handicapped or at-risk infants and preschoolers. As proof that science does influence social policy in a meaningful way, the amendments embody much of what has been learned from our years of research on early intervention. First, by extending the mandate of appropriate educational services for school-age children to cover the years before school, there is respect for that change as the child grows, and changes will certainly be more effective than efforts to treat the child at one point in time. The services provided are not limited to education, but also cover health and social needs, a broad intervention that holds promise of enhancing social competence in children who may be weak in one or more of these areas.

Like the original act, the amendments also recognize that parents have a profound influence on their children and must be an integral part of the intervention process. Thus, parents are part of a multidisciplinary team that plans and evaluates each child's program. 7he 1986 amendments also recognize that strong families are in the best position to strengthen their children's course of development. The law requires that each handicapped infant or toddler receive an Individualized Family Service Plan in which a case manager is assigned to each family to assess their needs and help them access whatever services they may require. When fully implemented, this law should do much to improve the adaptation of families with handicapped children, and to assure the early identification and long-term treatment of children who are retarded or have significant risk of functioning at a low level.

The types of intervention services I have talked about show that we now have some knowledge and are gaining the commitment to alleviate the problems associated with mild mental retardation. Of course, it would be more exciting to point to new methods that can cure retardation, but our knowledge base does not support expectations that changes in societal practices will lead to drastic changes in intelligence. We have also learned that we need not penalize people for being poor by raising their children for them, by abandoning them with the assumption of their probable inherent inferiority, or by recommending an identical regimen to improve their children's collective intelligence. But we do have reason to believe that several kinds of intervention can raise functional levels of intelligence for persons whose measured IQ is *commonly low. There is further evidence that a thoughtful coordination of these various interventions could help many children and their families to adapt better to society and to achieve a better quality of daily existence. In my opinion, this is a worthwhile and achievable goal of early intervention efforts.*

Additional attention to prevention through intervention is considered by Judy Howard, Professor of Clinical Pediatrics at the University of California at Los Angeles, with particular reference to the circumstances of infants in "chemically dependent families." She speaks to the behavioral and developmental aberrations frequent in children who have been prenatally exposed to illicit drugs and/or alcohol. The "continuum of reproductive casualty" ranges from spontaneous abortion and fetal death to prematurity, intrauterine growth retardation, mental retardation, learning problems, and normalcy. Improved systems will be needed to achieve effective coordinated treatment services.

Many systems are already in place to serve disadvantaged and/or biologically at-risk infants and children. For instance, children living under impoverished circumstances can receive health care funded through Medicare, and supplemental food can be provided through WIC programs. Infants and young children who are at risk or have developmental disabilities are eligible to receive services through developmental disabilities programs such as Regional Centers in California. Through Public Laws 94-142 and 99-457, (Education for all Handicapped Children Act of 1975 and the Education of the Handicapped Act Amendments of 1986), special education programs are and will be available to serve this special-needs population of children from birth, as well as their families. These programs also will provide services for infants who have been exposed prenatally to drugs. However, in order to appropriately serve this particular group of children and their families, some existing programs must be modified, and additional services must be considered.

Substance-abusing families bring unique challenges to our current service delivery system, where the primary caretaker (usually the parent) is responsible for bringing the child to health care and educational services. In order for a parent to ensure that the child is in the best of health and has educational opportunities, that parent must be able to locate and secure appropriate services. Based upon our knowledge about chemically dependent parents (i.e., altered mental status, the nature of addiction, the illegal activities revolving around drug use, etc.), health care providers, educators, and other involved professionals must be informed about the disorder of chemical dependency and its impact upon the daily life of the substance abuser. We cannot assume that chemically dependent parents will be able to advocate effectively for their children, work as team members in providing for their children's health and educational needs, and follow through with professional recommendations on a consistent basis.

If we want these "special-needs parents" to participate in the models we have developed, we will need to ensure that the parents themselves receive treatment for their addiction as well as parenting education and mental health services. Furthermore, in cases where children have been temporarily removed from their biologic parents' custody by court order and are under the care of extended family members or foster parents, or are in congregate care homes, we also will need to provide information to these temporary caregivers to help them obtain appropriate health and educational services for the children. We will need to identify the needs specific to *these various caregivers (including grandparents, aunts, and foster-families) and provide supportive services to them, to insure that they are able to participate fully in the children's individualized health and education plans.*

Providing these services will require the cooperation of professionals who traditionally have not been involved in meeting the health and educational needs of developmentally disabled children. Drug and alcohol treatment counselors, child protective services workers, law enforcement professionals, and members of the judicial system will need to join forces with medical and educational professionals so that chemically dependant families will receive coordinated treatment services for promoting a family unit that is healthy both physically and emotionally.

Herbert Cohen, Director of the Rose F. Kennedy University Affiliated Program at the Albert Einstein College of Medicine, addressed professional preparation and training to meet the needs of mothers and children with HIV infection. Children with congenital HIV infection are clearly in a multifaceted dilemma. The frequent expression of virus-induced encephalopathy is a major concern, but difficulties in the environmental factors (including maternal illness) are a concurrent liability. Support services for these children will reduce the developmental morbidity. Thoughtful training is needed for persons working in child development, child welfare, education, health care, and public planning, now and as the numbers of affected families and infants rise in the future.

Children with HIV infection not only may have neurodevelopmental disorders, but they may also have immunological, physical, sensory, social, behavioral, and educational impairments or difficulties. Therefore, care for these children may require extensive diagnostic and treatment services from many medical and allied health specialists, as well as from special educators and childcare personnel.

The complex nature of the child's and family's problems necessitates the development of a comprehensive service plan for the child and family.

The determination of the needs of the child and family or caretakers may vary considerably from child to child as well as with the time in the life of the child with a HIV infection that he or she is either first diagnosed as having a HIV infection or is brought to the attention of service providers.

Training needs include not only a familiarity with the previously presented information to convey an understanding of the causes, epidemiology, and course of the disease and its neurodevelopmental consequences, but also knowledge about the mechanisms for transmission of HIV infection, the forms of treatment, how to deal with the families and other caretakers, tights and entitlement of those infected, protection of confidentiality and who has the right to know, antidiscrimination measures and legal protection mechanisms, the complex moral and ethical issues associated with information sharing, tights to privacy, and the lights of care providers to know who is infected, what are the new treatment approaches, and the current data on prognosis.

Therefore, those who provide services for the child with a HIV infection and their family or caretakers must have an understanding of the disease, its cause, its social consequences, the devastation that it may cause, and its varied impact at different stages in the course of the disease.

As we learn more about HIV infection, we learn more about ourselves. For those that are in doubt about their capacity personally to care for persons who are HIV infected, it may be useful to remember the wisdom from a fortune cookie that stated "doubt is the beginning, not the end of wisdom. "

Travis Thompson, now the Director of the John F. Kennedy Center for Research on Education and Human Development, goes further in the discussion of the vulnerability of children in poverty. He speaks of undernutrition, inadequate prenatal care, exposure to infections pre- and postnatally, inadequate educational opportunities, and teenage pregnancy, as* disproportionately occurring to children born and raised in poverty. "This past century's experiences have changed us from the nation of naive optimists we once were." The time has come, he states, to set a new course for the future of our children.

Tackling problems associated with poverty is not a challenge for the faint of heart. The time is overdue that we stop shrinking from our responsibilities. Governmental agencies, businesses, and universities cannot solve these problems single-handedly, nor can any of these institutions be absolved of responsibility from joining the struggle. The 1990's will be the decade of combined efforts to solve societal problems that no single field of endeavor can reasonably expect to unravel alone. The results of yesterday's basic science will be today's applied research and become tomorrow's practice. It will be a time to turn difficult challenges into opportunities. It will be a time in which we will re-learn to take chances tackling problems that are truly important.

Authentic solutions are no longer rejected out of hand, but few political leaders are willing to take the chance of leading. Television and campaign financing have indelibly changed the meaning of leadership in America. One must look to leaders of an earlier time to find guidance. President John F. Kennedy's 1961 inaugural address called upon Americans to correct social inequalities, provide adequate health care and education for all Americans, and take dramatic new strides in technology. He said, 'All this will not be finished in the first one hundred days. Nor will it be finished in the first one thousand days, nor in the life of this Administration, nor even perhaps in our lifetime on this planet. But let us begin. " It is time to begin ... again. It is time to resume seriously working toward those noble goals, and to behave more responsibly as a people. It is time to capitalize on scientific knowledge so laboriously acquired over the past three decades and to strike out in search of new solutions where critical information is lacking. It is time to permit corrective feedback to work, to allow ourselves to be the kind of people we can and ought to be, for the sake of our children.

THE BREADTH OF FEDERAL INVOLVEMENT

The President's Committee on Mental Retardation created a landmark occasion in the February 1991 Summit Conference. An array of Federal, State and community agencies joined in support of a national event with a prevention theme. This offered a unique demonstration of the sweep of central governmental investment (Health and Human Services, Education) in the provision and sponsorship of prevention activities. Synchrony and common purpose were evident, and often collaboration as well. Resolves from the National Institute of Child Health and Human Development, Centers for Disease Control and Prevention, and the Office of Disease Prevention and Health Promotion are included in the Section on THE FUTURE. It is now relevant to review materials from the presentations of the other agencies. They provide a cogent perspective from that time (1991) of programmatic concerns regarding primary and secondary disability.

1. BROAD INTERESTS AND ACTIONS

Louis W. Sullivan, M.D., speaking as Secretary of Health and Human Services, listed four particular emphases in his Department that bear on improved options for mothers and children.

> *First, research. The President has proclaimed the 1990s as the "Decade of the Brain." We are expanding our commitment to research on the mind and the brain. Our research programs are wide-ranging. They include work at the molecular level, intervention programs targeted at high risk infants, and the use of computer assisted devices to help those with mental retardation learn to read.*
>
> *A second way to improve options and prevent the new morbidity is with immunization. As you know, we recently licensed the first vaccine effective in infants against meningitis associated with Hemophilus influenza type B, a leading cause of acquired mental retardation in the United States.*
>
> *There is a third way to increase options for mothers and children. We can prevent mental retardation in a vast number of cases if we can reach pregnant mothers and infants with medical care, nutrition, and the personal counseling that they desperately need in prenatal and neonatal stages.*
>
> *Let me say a word about improving access to programs. We are helping the States to adopt one-stop shopping initiatives that will make available, under one roof, the various health and social services that are targeted to pregnant mothers and infants. And, we have expanded Medicaid eligibility for pregnant women and infants to 133 percent of the poverty line. In addition, the President's proposed budget for next year projects that Medicaid outlays alone will be $3.8 billion for 2.4 million women and infants, an increase of $300 million over the previous fiscal year.*
>
> *You and I know that research, immunization, and accesses to care are vital. But so is a sense of personal responsibility for good health, the fourth way to improve options*

> *and prevent illness. We are calling for a new "culture of character" that nurtures values such as self-discipline and mutual concern for the health and well being of our friends, families, and neighbors.*

Deborah McFadden, former Commissioner of the Administration on Developmental Disabilities (ADD), gave examples of the substantial interest of the ADD in many aspects of prevention work.

> *Programs funded by the Administration on Developmental Disabilities have, of course, been involved in prevention activities for many years. Our Florida Developmental Disabilities Council is receiving an award at this conference for its work in this area. In Iowa, our Governor's Planning Council for Developmental Disabilities was instrumental in developing and advocating for the passage of a Senate Joint Resolution regarding the prevention of disabilities. Our University Affiliated Programs have been for twenty years in the forefront of training and research involving the prevention of disabilities. In a broader context, most of our advocacy efforts have been directed to ensuring that people with developmental disabilities are not given further disabilities through program models that promote dependence, idleness, isolation, and segregation. Rather, our goals for the entire program have become independence, productivity, and integration.*

2. THE WORLD OF CHILDREN

Vince L. Hutchins, Acting Director of the Maternal and !Child Health Bureau, U.S. Department of Health and Human Services, reflected on the longstanding effort in this field, in which Title V of the Social Security Act has been a central element.

> *In this century, numerous efforts at all levels of government have succeeded in improving maternal and child health. Advocates for children, including professional workers in the field, parents, private citizens, legislators, professional organizations, women's groups, and voluntary agencies, have been components of the constituency that has stimulated and monitored these efforts over the years.*

He further noted the salutary features of current Maternal and Child Health Block Grant applications, which include:

- *Statewide needs assessments.*
- *Planning for meeting identified needs.*
- *Assurance of at least 30 percent assignment for preventive and primary care services.*
- *Assurance of at least 30 percent for Children with Special Health Needs services.*
- *Assurance that the Fiscal Year 1989 level of State effort will be maintained.*
- *Provision for Title V agency participation in interagency coordination with related programs.*
- *Provision for identification of, and application assistance for, Medicaid-eligible pregnant women and infants.*

Wade F. Horn, former Commissioner, Administration for Children, Youth, and Families (ACYF), U.S. Department of Health and Human Services, spoke of the strong and diverse contributions of that agency.

> *HEAD START, now concluding its 25th year, is a comprehensive child development program currently serving 550, 000 low-income preschool children and their families in 2,000 communities across the country. A minimum of 10percent of the enrollment opportunities in each State must be made available to children with disabilities, including mental retardation. Head Start has surpassed this requirement in each of the last 17 years; currently, 13 percent of the enrollment is comprised of children with disabilities.*
>
> *Head Start's four program components emphasize cognitive and language development, socio-emotional development, physical and mental health, nutrition, social services and parent involvement. Together, these components play an important part in the prevention and amelioration of mental retardation and other developmental delays for Head Start children.*
>
> *Among programs administered by the CHILDREN'S BUREAU that affect children with mental retardation, their families, and other caregivers are projects that offer respite care for families who adopt children with special needs, respite care and temporary crisis nurseries for children with disabilities, and specialized family foster care for older children with mental, emotional, or physical disabilities.*
>
> *Under the Abandoned Infants Assistance Act of 1988, Public Law 100-505, the Children's Bureau has funded 24 demonstration projects to prevent the abandonment of infants born to mothers with Human Immunodeficiency Virus infection, Acquired Immune Deficiency Syndrome and other medical problems. In addition to addressing the special needs of the babies who are at high risk of developmental delay and other troubled outcomes, the projects are developing ways to identify mothers at risk of abandoning their children and to provide services to help them bond with their infants and prepare to care for them at home. The projects are also preparing infants who cannot reside with their natural families for placement in family foster homes, and recruiting and training caregivers.*
>
> *Several programs supported over the last five years by the NATIONAL CEN7ER ON CHILD ABUSE AAD NEGLECT (NCCAN) to prevent child maltreatment also are particularly relevant to the prevention or amelioration of mental retardation. Between 1986 and 1989J. NCCAN funded projects were designed to reduce the risk of developmental delay among infants of chemically dependent mothers and to improve the childrearing skills of teen parents. More recently, the NCCAN awarded-based prevention programs that grants for model comprehensive community include prenatal health care, parenting education and support programs for new parents, and support programs such as respite care and crisis nurseries for parents under stress. The NCCAN also funds a clearinghouse to assist agencies that work with another high-risk group of children—disabled infants with life-threatening conditions. The National Information*

> *Clearinghouse on Disabled Infants with Life-Threatening Conditions disseminates information on treatment procedures, and services and resources available to infants and their families, including social and parent support services.*
>
> *Among the research studies supported by the NCCAN are two that have examined possible links between child maltreatment and mental retardation. Researchers at Cornell University and the University of Georgia suggest that child maltreatment may adversely affect the life chances of any child, particularly children with mental retardation who are at risk for academic failure and social/emotional dysfunction. Prevention programs targeted to child maltreatment may be of help in reducing such risk.*
>
> *Finally, the ACYF recognizes that coordination with other agencies concerned with the prevention and amelioration of disabilities is essential for successful intervention. Accordingly, the ACYF is a member of the Federal Interagency Coordinating Council (FICC), the Federal-level counterpart of the State Interagency Coordinating Councils required under the Individuals with Disabilities Education Act ODEA). A subcommittee of the FICC is currently developing an interagency agreement between the Department of Health and Human Services and the Department of Education, involving the A CYF, the Administration for Developmental Disabilities, the Maternal and Child Health Bureau, the Social Security Administration, the National Institute of Mental Health, the Centers for Disease Control and Prevention, and the Office of Special Education Programs. Under this agreement, the agencies will work together to identify infants and children with disabilities who are in need of services, and will jointly coordinate and provide services and referrals for children and families.*

Supports for children and families in the circumstance of at risk or disability is part of the province of the Social Security Administration (SSA), as discussed by Gwendolyn S. King, the former Commissioner. "The SSA can work in concert with other efforts to try to minimize the socio-economic factors that often tragically prevent a child from getting a happy and healthy start in life."

> *Currently, through our Supplemental Security Income (SSI) program, the Social Security Administration provides monthly cash assistance totaling about $121 million to some 312,000 children with disabilities and their families who have limited income and resources. Of these children, more than 111,000 have mental retardation.*
>
> *While dollars cannot make a child's disability go away and while SSI will not entirely eliminate financial difficulties, monthly benefits from this program can make a difference by providing basic necessities for a child with disabilities and his or her family. Eligibility in the program also may open the door for Medicaid eligibility and other State and Federal services.*
>
> *For those enrolled and receiving benefits, the SSI program has helped. But I must say candidly that SSI is not yet an unqualified success. Not when there are still people in cities, town, and communities across this nation who need its help and are entitled to it,*

> *but are not receiving it. Not when there are children whose lives could be set on a different course if they were receiving these benefits.*

3. CREATIVE EDUCATION

Michael E. Vader, former Deputy Assistant Secretary for the Office o Special Education and Rehabilitation Services (OSERS), U.S. Department of Education, reported on the extraordinary new developments in education, which have major prevention implications.

> *Part H of the Education of the Handicapped Act Amendments of 1986, (P.L. 99-457) is a formula grant program of assistance to States to help them develop a comprehensive, interagency program of early intervention for infants, toddlers, and their families. Not only are children from birth through two years of age eligible for services under Part H, but in addition, States may elect to serve infants and toddlers who are at risk for delay if early intervention services are not provided.*
>
> *One of the most significant features of the Pan H Program is its emphasis on the family. Both children and families must be assessed to determine their strengths and needs, and early intervention services must be documented in an individualized family service plan. Early intervention services may include case management services, family training services, health and medical services, and others. We're very excited about the future of programs that provide early intervention services for infants and toddlers.*
>
> *In our work at the OSERS, we have established a mission to ensure that all individuals with disabilities realize their optimal potential, productivity, and participation in our society. Young children have so much potential. They are at the beginning of their lives. By making sure that young children with disabilities and their families receive the support and intervention that is needed, we have the best chance of helping them to reach their full potential. Even from the time of early childhood, our goals must be focused on outcomes and the long-term productivity of children and families. We can do this only if there is a long-standing commitment between parents and professionals to work together in partnership to provide the necessary services.*
>
> *This need for full participation in the planning process is also true at the Federal level. Our effort to expand programming for infants means that we will be dealing with many new issues. I think it is vitally important to the future of people with disabilities that we cultivate hope and confidence. It is only when we possess these attitudes that we can embrace and master change. If we respond positively, we will continue to develop the innovations required to ensure equal opportunity for persons with disabilities.*

The scope of special education is broadening, and now includes important supports for children with special needs to allow their best progress, as recounted by Judy Schrag, former Director of the Office of Special Education Programs in the Department of Education.

> *There are other changing populations on which we are focusing our programs in the Office of Special Education to support efforts within the States. For example, we*

know that the schools are faced with increased numbers of severely handicapped, medically-fragile children who might have died a few years ago but are being saved and entering our classrooms as a result of wonderful medical technology. Another aspect of the changing special education population is that new medications are being used for cancer, epilepsy, and emotional problems, including some that are appearing to permanently affect learning skills. Increased numbers of scoliosis students are now returning to school without extended home and extended hospital stays.

Other aspects of the changing population include children with cystic fibrosis, muscular dystrophy, and hearing defects who are living longer than in previous years and are, therefore, entering our schools. In addition, there are increased numbers of babies with HIV infection, as well as greater ethnic diversity. Congress has recognized younger and more impacted students with emotional disturbance and mental health needs with a new discretionary program in the Individuals with Disabilities Education Act (IDEA), Public Law 99-457, which is the re-authorization of the Education of the Handicapped Act. We have other changes in our special education population. Certainly, this increased diversity demands a whole child, coordinated service delivery approach. There are many exciting new linkages being formed across special education, social services,, and health services within the States. Today only allows highlighting some of those. The CASP projects and Robert Wood Johnson-supported projects for children and families with mental health concerns are some examples.

4. CONTINUING INTERVENTION FOR PERSONS WITH DISABILITY

A modern component of the prevention spectrum relates to actions that conserve the strengths and functional potential of persons with disability, modulating the impairment and reinforcing the quality of life. William Graves, Director of the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education indicated that agency's commitment in this area.

About $3.6 million has been programmed for disability and rehabilitation research in the area of mental retardation. What kinds of projects are supported? A Rehabilitation Research Training Center (RRTQ is funded at the University of Minnesota to improve community integration for persons with mental retardation. 7'here is a second RRTC funded at Syracuse University to identify and focus its efforts on actual practices for operating community residences for children and adults with mental retardation. There is an RRTC at the Cincinnati Center for Developmental Disorders to provide expertise in helping older people with mental retardation integrate into community life. There is an RRTC at Virginia Commonwealth University designed to improve employment outcomes for individuals with mental retardation by using the supported employment model. These four activities are examples of the kinds of work being carried on by N1DRR grantees that promote the integration and inclusion of individuals with mental retardation into the community. Funding also occurs in the Field-Initiated Research, Innovation Grant, and Small Business Innovative Research Program.

It is within the Independent Living Centers that some of the most substantial efforts are occurring regarding the prevention of secondary conditions--the phenomena that have so often intruded on the personal status and quality of life experienced by people with disability. The self-help training and supported efforts provided by these centers are of seminal importance in minimizing the occurrence of secondary conditions. Nell Carney, former Commissioner of the Rehabilitation Services Administration (RSA), U.S. Department of Education, spoke of RSA's commitment to assist here.

> *Title VII of the Rehabilitation Act authorizes RSA to provide independent living services in three categories: Pall A, grants to State vocational rehabilitation (VR) agencies; Part B, funding for centers for independent living; and Part C, independent living programs for the older, blind population. Overall, approximately $67 million annually goes to support the independent living programs. The thrust of these programs is to improve the quality of life for millions of Americans with disabilities through such services as peer counseling, community integration, assistive technology, and many other services designed specifically to elevate or maintain the level of independence of the individual.*

The particular situation of elderly persons, with or at risk for disability, is receiving fresh consideration. Joyce Berry, former Commissioner of the Administration on Aging (AoA), U.S. Department of Health and Human Services, presented ideas regarding collaborative efforts on behalf of senior citizens who have special needs or are at risk for disability.

> *The Older Americans Act programs offer a wealth of opportunity in terms of making sure that adults with mental retardation and their caregivers remain in the community, which is where they want to be. Less than five percent of older people are, in fact, in institutions. Older people want to stay in the community and seniors with mental retardation are no different in this respect. Their caregivers, however, need support to keep their children with mental retardation outside of institutions. Older adults with mental retardation need a whole range of services. You all know what they are. They need adult day care. They need homemaker services, home health aides, home-delivered meals, transportation services and so on.*
>
> *Commissioner McFadden and I have just recently funded four projects to strengthen assistance to persons with disabilities. We have projects in New York, Virginia, Wisconsin, and Mississippi where we are trying to forge linkage between the aging network and the networks servicing persons with developmental disabilities in order to enhance supportive services.*
>
> *The AoA has decided to place great emphasis on that smaller but sizeable group of older people who are at-risk, and this includes the target group that we are concerned about today. Essentially what we are trying to do through the National Eldercare Campaign is to heighten public awareness of the needs of older persons at-risk and programs available to help them.*

Commissioner King, for example, has expressed her concern about the many seniors who still do not know about Social Security Income (SSI), and we have been trying to work together on improving outreach to enroll seniors.

ACTION IN STATE PROGRAMS

For the 1991 Summit, the President's Committee on Mental Retardation invited four States--Florida, Iowa, New Jersey, and California--to make brief presentations of exemplary work going on in their programs. Three of these had received capacity-building grants from the Centers for Disease Control and Prevention, but all previously had strong commitments in this area. To date the implementation of prevention activities has commonly had a base in State agencies, and the ones presented here are among the best. Described in the projects are efforts in creating improved pregnancy outcome, avoidance of adolescent pregnancy, prevention of lead poisoning, building public awareness, and delivering genetic services.

FL0RIDA

George Schmidt, Program Manager of Florida's Interagency Office of Disability Prevention, reported on the State's Outreach Childbirth Education Project. This effort was designed to reach medically indigent families in the Florida Adult and Community Education Centers, with a potential cohort of 60,000 expectant parents. The anticipated outcomes of the instruction are:

Improved prenatal care
Reduction in the incidence of low birthweight
Reduction in the number of unwanted second pregnancies
Improved literacy skills to enhance job opportunities
Improved ability to access systems of support and health care.

These affirmative plans were predicated on the agency's resolve that "Florida's future is her children..."

The Florida Department of Education (ED), formed a partnership with the Florida Department of Health and Rehabilitative Services (DBRS), the March of Dimes Birth Defects Foundation (MOD), the Coalition of Florida Childbirth Educators (CFCE), and the Florida Healthy Mothers/Healthy Babies (HMIHB) Coalition to achieve the following program objectives:

1. Production of curricula for training of outreach childbirth educators and for teaching prenatal and childbirth classes for families with low literacy skills. These curricula are designed to meet the learning needs of poor readers, to broker adult and community education programs, and to encourage reading in the home.

2. Establishment of a mechanism to provide childbirth classes to all low-income families in Florida. Attracting low-income, low-literacy, expectant parents to childbirth classes is a highly effective outreach tool for other literacy and adult education programs. Outreach classes were begun at 33 new sites in 1989. A recent survey of County Public Health Units (CPHUs) in Florida revealed that approximately 15,000 of their maternity clients are being served by the outreach project

3. Establishment of a mechanism for ongoing recruitment and training of outreach teachers. In 1989 alone, over 100 teachers were trained. Most completing the course are hospital and public health nurses who now teach in Adult and Community Education Centers throughout the State.

4. Strengthening of the cooperative relationship between education and health organizations in Florida. At the State level joint funding between the DOE and the DHRS enabled the MOD, with support from the CFCE and HMIHB Coalition, to develop and implement the project at the local level.

5. Development of a program model which can be disseminated to other States.

IOWA

One of the many projects in Iowa's Office of Disability Prevention was described by Roger Chapman, Program Manager. This involved establishment of a planning Task Force, comprised of local professionals and consumers, in the economically pressed rural community of Ottumwa, Iowa. While the work of the task force was sponsored by the Office of Disability Prevention, the interventions were planned to become a self-sustaining part of the community infrastructure.

> *When asked what could be done locally, the taskforce chose to focus upon the prevention of adolescent and unwanted pregnancies. Specifically, the committee suggested educational programs in the public school system. 7he local high school had long resisted any effort to include educational material focused on human sexuality in regular classes. However, this dramatically changed after a workshop was presented by the project that documented the local problem. A high school counselor attending this conference approached the project coordinator with a proposal for a class.*
>
> *After conferring with the project coordinator, the counselor approached the school superintendent with this idea. She received an enthusiastic endorsement. 7he coordinator then met with the high school counselors to work out logistical details. At this point considerable resistance was encountered. However, by then the question was who would do it and when. not if it would be done. The end result was a five-class curriculum entitled "Postponing Sexual Involvement" taught to all Ottumwa ninth graders in English class.*
>
> *Next the school nurse on the taskforce approached the Alternative School Principal with the same idea. The Alternative School conducts classes for students who drop out of regular high school. The idea was also enthusiastically received. The result was two classes a week taught at the Ottumwa Alternative High School focused upon relationships and parenting.*
>
> *The Pediatrician on the taskforce suggested another way to approach low birth weight prevention was to implement smoking cessation and teen prenatal classes. Both classes are currently being taught by the project.*

The point of all this is to illustrate that local people who are committed to a prevention program are in the best position to make it work By listening to local people and incorporating appropriate suggestions, the way is cleared for invested people to use existing linkages to meet program objectives.

Establishing local coalitions was an essential component in making the project work. Prior to the implementation of the project, active involvement was sought from the local medical society. Several discussions were held with local physicians to discuss the project and solicit their input. The project was presented as complementing, not competing with, existing services. All too often new health-related programs require local health care providers to contribute time or other scarce resources. This project made no such request. In fact, analysis of project data would serve to enhance existing health services to area families.

Community awareness of the project was another essential component of moving from planning to implementation. At the beginning of the project, several local events were conducted to introduce the project to the community. An "open house " was attended by several area professionals. The resource library was of particular interest. A "media meeting" was planned and conducted. Local media representatives (radio, television, and newspaper) were invited to hear a panel of taskforce members talk about teen pregnancy in southern Iowa and project objectives. The data that was presented was supplied by field staff from the Office of Disability Prevention. The outcome of this was several newspaper feature articles and radio talk show appearances. The information presented was well received because it involved local people discussing local problems.

Community awareness should be an ongoing process. In recognition of this, taskforce co-chairs have done a number of educational presentations to community groups discussing teenage pregnancy and project objectives. Apart from the obvious benefit of community awareness, such presentations continue to strengthen investment and ownership in the project by the presenters.

Public service announcements continue to publicize project activity. These include use of radio, television, and newspapers; posters in laundromats and on buses; project information stuffed in power bills; and printed on grocery sacks.

NEW JERSEY

Deborah Cohen, Director of New Jersey's Office for Prevention of Mental Retardation and Developmental Disabilities, provided an analysis of the factors that may influence variations in the speed and effectiveness by which prevention plans move on to implementation. Ideally, she states, the following elements should be present:

- unchallenged, recognizable leadership
- consensus about the social good
- mobilization of good karma in gear

- making magic without money
- suppression of ego for glory sharing.

She then illustrated these features in action regarding the establishment of an effective program for prevention of lead poisoning.

The setting for leadership was assured by the presence of a Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities. The Council an Interagency Lead Poisoning Prevention Task Force was organized with critically important membership from health, housing, environment, education, and social services; and with help from community advocates, universities, and professional groups.

The social -good consensus was soon secured:

> *From its first meeting, the taskforce members explicitly put forth its philosophy: No person's life should be endangered or compromised due to lead poisoning. There was almost no discussion within the taskforce about the value of reaching resolution with respect to the lead problem.*
>
> *This consensus has resulted in several important organizational outcomes that have matured over time. First, it is now recognized that the whole is greater than its parts, meaning that no single agency could resolve the problem on its own. During the earliest meetings, members of the task force, most of whom are in middle management, expressed their sense of feeling overwhelmed by the magnitude of the problem. By providing a forum through which individual members could be recognized for their contribution to the whole, a sense of achievement replaced feelings of frustration.*
>
> *Second, it is now recognized that no single agency has a role greater than others in resolving the problem. The need for interdepartmental cooperation in defining achievable objectives encouraged understanding of the strengths and limits of each agency. Thus, while early discussions may have involved finger-pointing and casting blame, such debates are now tempered by more realistic expectations of the capabilities and the political realities of each department.*
>
> *Finally, attempts to develop strategies that would move the issue of lead higher up on the political agenda were originally met with skepticism, as individual members were uncertain about the response of their Commissioners. The taskforce resolved this issue by drafting an Action Agenda that assigned responsibility to each agency, specified roles for each Commissioner, and recommended incremental approaches that each agency could implement. The Action Agenda was then endorsed by the Governor's Council and forwarded to the Commissioners for their review and approval.*
>
> *This approach removed responsibility from the individual members and made the Governor's Council and taskforce the accountable agents. It has -also had the benefit of insuring that the leadership from each department was in consensus about the value of lead poisoning prevention as a social good.*

CALIF0RNIA

California has been involved in prevention planning for a long time. Raymond Peterson, Director of the San Diego Regional Center, presented a review of some recent work. He spoke particularly about the activities of the Association of Regional Center Agencies (ARCA), which has a key role.

> *The ARCA's Prevention Committee has three active subcommittees that address prevention activities in California. These subcommittees are: 1) Persons at Risk of Parenting a Child with a Developmental Disability (genetics); 2) Infants at Risk of Becoming Developmentally Disabled; and 3) Public Information and Public Awareness. The most important is Public Information/Public Awareness because, no matter how sophisticated we are from a scientific standpoint, we will have little impact on reducing the incidence of mental retardation or reducing mortality or morbidity, if the public or consumer is not informed and does not have access to what is k7zown to assist in assuring a healthy and productive life.*
>
> *Public awareness activities include distribution of materials developed by the Committee about selected prevention topics to each of the 21 regional centers, so that information can be disseminated to persons in all of the 58 counties in California. Public media is used and is coordinated between the regional centers and the State Department of Developmental Services. The topics that are targeted for this year are:*
>
> - *Substance Abuse and Life Styles*
> - *Prevention of Childhood Injury*
> - *Near-Drowning Pediatrics AIDS*
> - *Lead Poisoning*

A local project of interest is the program to provide genetic counseling, prenatal diagnosis, and other genetic services in the San Diego Regional Center. Acknowledging the potential barriers to effective use of such services by the large minority population that lives in San Diego, a special effort was made to reach these persons.

> *This project demonstrated that individuals and families in Latino and Southeast Asian cultures are receptive to and will utilize genetic counseling information and services when such information and services are made accessible to them. Since the project terminated, we have maintained the two bilingual positions (Spanish and Vietnamese) to assure the services will continue to be accessible to these populations. We have also expanded prevention services to address the needs of Southeast Asian refugees in our community who are faced with cultural and language barriers that limit the use of community services. The model for the Southeast Asian Developmental Disabilities Project (SEADD) uses bilingual and bicultural case managers from the Vietnamese, Cambodian, Laotian, and Hmong communities, who have been trained to assist families to obtain services for high-risk infants, and genetic services. By targeting this population and providing outreach to families who have immigrated to the United States, we have*

assisted individuals to assimilate into the community and to obtain services as a part of our efforts to prevent or ameliorate childhood disabling conditions. This has been a very successful and exciting project.

RECOMMENDATIONS

Stimulated by the Statement of Occasion, the Keynote Address, and the five Panels of speakers, the Conference Work Groups reflected on possible routes to achievement of the expressed goals. These gatherings compiled a strong and relevant listing of recommendations focused on the theme of prevention of disability related to the "new morbidity."

These recommendations, originally 31 in number, speak primarily to three vital tracks: (1) RESEARCH NEEDS, for improvement of the knowledge base about disability, (2) BASIC SUPPORTS FOR ALL FAMILIES, to assure egalitarian access for life needs, and (3) IMPROVED PLANNING FOR PREVENTION for thoughtful mobilization of resources.

RECOMMENDATIONS

1. Research Needs

Continue research efforts at the national, State, and local level into known and unknown etiologic factors in mental retardation and related disabilities.

Encourage interdisciplinary efforts to outline and implement effective methods for identifying children "at risk."

Establish a network of epidemiology developmental disability centers to develop methods useful for surveillance, keep "scorecards," engage in health services research, and provide training for persons interested in epidemiology.

Institute a national database to track indicators of the adequacy of efforts to reduce the incidence and ameliorate the effects of disabilities, including the indicators for prenatal care, low birthweight, and immunization.

2. Basic Supports for All Families

Extend public education with families downward, beginning at birth and using the home visitor concept.

Obtain funds for educational programs and services into the hands of people who need them, using a "children's allowance model."

Professionalize the occupation of childcare provision into a career ladder concept, starting at the vocational level and working through advancing levels of proficiency.

Make child care an integral part of the public school system.

Make mandatory the use of meaningful curricula for school-based education in preparation for parenthood, beginning at the late elementary level and continuing through high school.

Improve the process by which people access services, particularly for minorities and disadvantaged populations, using "consumer-friendly" strategies that reduce the possibility that consumers will see the process itself as a barrier.

Encourage and utilize family-centered approaches to service delivery, involving fathers, extended family members, and "significant others" in the process.

Support communities in such areas as employment, housing, nutrition, safety, and environment.

Make health care accessible to all, and establish universal health insurance.

3. Improved Planning for Prevention

Invite and support strong involvement of parents on prevention coalitions.

Involve more people with disabilities in planning efforts, and invite their input regarding the direction in which prevention planning should be focused.

Use peer mentoring to encourage the involvement of individuals who represent disadvantaged populations on prevention coalitions at the local, State, and national levels.

Invite representatives of agencies that serve persons with substance abuse or related problems to serve on prevention coalitions.

Establish alliances with Governors and Legislators at the State and national level who have demonstrated interest in disabilities, and make use of their influence and visibility to address the needs of children, mothers, and families.

Make more effective use of the capability of the media to portray unmet needs and address solutions to these needs.

Involve private industry in State planning efforts and focus on productivity.

Prevention planners at the State level should determine what programs and services are needed and wanted, and outline a strategy for addressing the assessed needs, based on analysis of the particular circumstances that characterize the State.

Identify and address attitudinal barriers to the comprehensive planning and delivery of services.

Encourage and support the establishment of more Federal, State, and local interagency alliances around topical issues.

Establish a national advisory committee, heavily consumer driven, and a Federal interagency council, as recommended in the Institute of Medicine publication, Disability in America.

Encourage the establishment and maintenance of an Office of Prevention in each State that is independent, rather than a part of the institutionalized bureaucracy within the State.

OBSERVATIONS AND COMMENTS ON ADEQUACY OF THE NATIONAL EFFORT TO REDUCE THE INCIDENCE AND AMELIORATE THE EFFECTS OF MENTAL RETARDATION AND RELATED DEVELOPMENTAL DISABILITIES

The 25th Anniversary Summit Conference of the President's Committee on Mental Retardation in February 1991 provided a comprehensive profile of the current status of the national effort for prevention of developmental disabilities. The substantial nature of the presentations confirmed that the Prevention Movement is alive and well. This movement began over 20 years ago, heavily motivated by consumer outreach and implemented by parent organizations and State coalitions. In the early days many other Federal entities, such as the Maternal and Child Health Bureau of the Health Resources and Services Administration and the CDC, made important contributions in prevention and the PCMR has provided national leadership and inspiration from the start.

The first decades of the Prevention Movement had some striking successes, particularly in the area of biomedically-based causes of mental retardation. This included near-elimination of kernicterus (from Rh disease), of the major affects of PKU, of encephalopathy from congenital rubella and from measles encephalitis, and of the principal incidence of Tay-Sachs disease. Genetic counseling became much more accurate, and prenatal diagnosis of important conditions was often possible. Improved outlook for preterm babies was provided by the field of neonatology and the establishment of regional newborn intensive care units. Screening for lead poisoning, and deleading of involved homes, was more widely practiced. Increasing utilization of programs with early intervention for stimulation, nurturance, and education of infants at risk had valuable outcomes for both child and family.

Now, however, as recent campaigns have been focused on broader social ills that result in suboptimal progress for children the record has become very frustrating. New liabilities for mothers and children, or entrenchment of continuing disadvantages, have placed significant segments of the population in jeopardy (the "new morbidity"). Numerous key indicators of child health and/or opportunity have failed to improve, even when energetic preventive activities have been marshaled. These include low birthweight rates, the racial disparity in infant mortality rates, teenage fertility rates, substance abuse in pregnancy, birth incidence of HIV infection, and reports of child abuse. These concerns were the origin of the PCMR's selection of the theme, "Preventing the New Morbidity" for the 1991 conference.

Three presentations at the Summit spoke to important new Federal direction and assistance in the prevention effort. The first and most important of these has been the formation (in 1988) of the Disability Prevention Program at the Centers for Disease Control in Atlanta. To date this program, originally spurred by the National Council on Disability, has provided capacity-building grants to 28 States. These will assist in the formation of State Prevention Plans and State Offices of Prevention, as well as bring support for community-based projects and various special studies. The second valuable force has been the release in 1991 by the Institute of Medicine of the report, "Disability in America: Toward a National Agenda for Prevention." And, finally, the appearance in 1990 of "Healthy People 2000," a modern tally of national goals and objectives relating to health and prevention of disease, establishes some respected targets for workers in developmental disabilities. All three of these achievements give special attention to prevention of secondary conditions in persons with disabilities.

There is indeed, a lot of activity currently within the scope of prevention of developmental disabilities. It must be admitted, however, that most of the substantial victories are occurring for concrete, low or moderate incidence conditions. While we succeed on a limited front, deleterious forces still seem to be gaining on us. There is no evidence to suggest that total prevalence scores can document any breakthrough. In many regards the current assignments (such as within the "new morbidity") are more numerous and tougher.

The 25 recommendations derived during the Summit Conference are areas needing attention--such as research for etiology and epidemiology, mandatory curricula in preparation for parenthood, "consumer-friendly" services to remove barriers, assistance in employment, housing, and environment, and universal health insurance. It was also acknowledged that the Nation needs more consumer-based planning and interagency alliances. The Institute of Medicine (10M) suggested a national advisory committee and Federal interagency council. It was the judgment of the Summit Conference that for rectification of social ills, the country needs a mentality supporting social programs and true collaboration.

AGENCIES, ORGANIZATIONS, FOUNDATIONS, INSTITUTIONS INSTRUMENTAL IN FACILITATING EARLY IMPLEMENTATION OF PROGRAMS AND SERVICES KNOWN TO BE EFFECTIVE IN MINIMIZING THE OCCURRENCE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

The positive forces at the "front line" for the prevention of mental retardation and developmental disabilities work within the domains of public health, social services and child welfare, education, and public assistance. These domains include a vast array of human services, devoted to the promotion of the condition of individuals, families, and society. It has often been noted that virtually all programs that are supportive for children in general can also be considered as preventive for developmental disorder. When a final tally is made of who is currently helping or can help, the list is huge. Beyond the direct territories mentioned above, there are background supportive elements as well, such as housing, employment, drug treatment, research, professional training, and advocacy that affect the final adequacy of child and family life.

Many of the Federal agencies that have a facilitative role in early access to effective programs are described in the section of this report on "The Breadth of Federal Involvement." The most common sequence, of course, is assistance to State programs where direct client contact occurs. Included in the U.S. Department of Health and Human Services are: the Maternal and Child Health Bureau (support to State health departments via the Block Grants), the Administration on Developmental Disabilities (programs of the State Developmental Disabilities Councils and the University Affiliated Programs), the contributions of the Centers for Disease Control (Disability Prevention Program), with its State grants for local projects, the Administration for Children, Youth, and Families (Head Start, Children's Bureau, and the National Center on Child Abuse and Neglect); and in the U.S. Department of Education, the Office of Special Education and Rehabilitative Services (special reference to The Education of the Handicapped Act Amendments of 1986, P.L. 99-457). Ultimately one can also trace the work of the President's Committee on Mental Retardation, the Health Care Financing Administration, the National Institute of Child Health and Human Development, and the Office of Disease Prevention and Health Promotion.

The immediate implementation of prevention programs is often set by State agencies, and carried out by them or by city and community facilities. Within the health area this includes family planning, genetic counseling, prenatal care, newborn screening, infant tracking, developmental screening, lead screening, prevention of HIV infection, youth programs, etc. Community health centers and community nursing agencies are sensitive foci for critical preventive services. Departments of Education and the School Districts provide developmental screening, early intervention programs, and family life curricula. Social Service agencies offer child protective services and child welfare services. Public Welfare or Public Assistance agencies are charged with supporting needy families, and various advocacy centers (e.g. "Office for Children") provide monitoring of services. In some States the Department of Mental Retardation or of Developmental Disabilities offer supportive programs for young children, and the Developmental Disabilities Council may sponsor innovative interventions. The State's Office for Disability Prevention, when established, can coordinate and enhance the accessibility of these activities.

Activities within the private sector have a sensitive place in the service world, such as the countless programs by Arc organizations for young children at a State or district level and local branches of United Cerebral Palsy. Family guidance, in the genetic service area, parent-to-parent support, and in advice about treatments, is provided by groups such as the National Tay-Sachs and Allied Diseases Association, the National MPS Society, the National Down Syndrome Congress, and the Epilepsy Foundation, or their affiliates. Family Planning Councils greatly supplement State facilities in counseling for contraception or pregnancy planning. University Affiliated Programs (UAPs) and teaching hospitals may offer unique preventive services, and the private philanthropic foundations (Robert Wood Johnson, Cox, Noonan, etc.) are also bringing support to new initiatives for prevention.

APPENDICES:

Appendix A – PCMR April, 1993

Appendix B – PCMR Executives Committee and Subcommittee Membership

Appendix C – PCMR February, 1991

Appendix D – Prevention Summit Program Participants and Exhibitors

APPENDIX A

President's Committee on Mental Retardation
April, 1993

Donna E. Shalala, Chair
Secretary, U.S. Department of Health and Human Services
Albert L. Anderson, D.D.S., Vice Chair

<u>EX officio Members</u>:

The Honorable Henry Cisneros, Secretary, U.S. Department of Housing and Urban Development
The Honorable Federico Pena, Secretary, U.S. Department of Transportation
The Honorable Robert B. Reich, Secretary, U.S. Department of Labor
The Honorable Janet Reno, Attorney General, U.S. Department of Justice
The Honorable Richard M. Riley, Secretary, U.S. Department of Education
Mr. John Seal, Acting Director, ACTION

<u>Citizen Members:</u>

Albert L. Anderson, D.D.S.
Kenneth L. Barun
Norma G. Bordelon
Robert E. Brown
Patricia A. Caggiano
Dorothy C. Clark, R.N.
Jack T. Dulworth
Linda Felner
Patricia Foss
Marcia Frey
Thomas G. Gunnings, Ph.D.
Karen Moffitt, Ph.D.
Dagne B. Olsen
Betty B. Osman, Ph.D.
Charlotte B. Parkinson, D.S.W.
Edwina Dalton Phillips
J. Alfred Rider, M.D., Ph.D.
Donald Sapaugh
Mark A. Shiffrin
E. Duane Thompson
Martin S. Ulan

APPENDIX B

PCMR EXECUTIVE COMMITTEE AND SUBCOMMITTEE MEMBERSHIP

April, 1993

Executive Committee

Albert L. Anderson, D.D.S., Vice Chair
Dorothy C. Clark, R.N., First Vice Chair
Kenneth Barun
Dagne B. Olsen
Betty B. Osman, Ph.D.

Family and Community Services

Robert E. Brown, Chair
E. Duane Thompson, Co-Chair
Norma G. Bordelon
Linda Felner
Marcia Frey
Charlotte B. Parkinson, D.S.W.
Edwina Dalton Phillips
Martin S. Ulan

Ex Officio Members:
Paul Hippolitus, DoL
Rey Tejada, ACTION
Michael Vader, DoE

Full Citizenship and Justice

Dagne B. Olsen, Chair
Thomas Gunnings, Ph.D., Co-Chair
Patricia A. Caggiano
Dorothy C. Clark, R.N.
Jack T. Dulworth
Mark A. Shiffrin

Ex Officio Members:
Louis Stewart, DoJ
Robert Ashby, DoT
Margaret Milner, HUD

Prevention

Betty B. Osman, Ph.D., Chair
J. Alfred Rider, M.D., Ph.D., Co-Chair
Dorothy C. Clark, R.N.
Patricia Foss
Karen Moffitt, Ph.D.
Donald Sapaugh

Public Awareness

Kenneth Barun, Chair
Jack T. Dulworth, Co-Chair
Robert E. Brown
Dorothy C. Clark, R.N.
Patricia Foss
Karen Moffitt, Ph.D.
Dagne B. Olsen

Betty B. Osman, Ph.D
Donald Sapaugh

APPENDIX C

President's Committee on Mental Retardation
February 1991

Louis W. Sullivan, M.D., Chair
Secretary, U.S. Department of Health and Human Services
Albert L. Anderson, D.D.S., Vice Chair

Ex Officio Members

The Honorable Lauro Cavazos, Secretary, U.S. Department of Education
The Honorable Elizabeth Dole, Secretary, U.S. Department of Labor
The Honorable Jack Kemp, Secretary, U.S. Department of Housing & Urban Development
The Honorable Jane A. Kenny, Director, ACTION
The Honorable Richard Thornburgh, Attorney General, U.S. Department of Justice

Citizen Members

Albert L. Anderson, D.D.S.
Kenneth L. Barun
Robert E. Brown
Patricia A. Caggiano
Dorothy C. Clark, R.N.
Linda Felner
Jack T. Dulworth
Vincent C. Gray
Ruth Govorchin
Jean G. Gumerson
Matthew G. Guglielmo
William Kerby Hummer, M.D.
Thomas Gunnings, Ph.D.
Dagne B. Olsen
Betty B. Osman, Ph.D.
Dean B. Owens
Edwina Dalton Phillips
J. Alfred Rider, M.D., Ph.D.
E. Duane Thompson
George M. Wilson

APPENDIX D
PROGRAM PARTICIPANTS AND EXHIBITORS

PCMR SUMMIT ON THE NATIONAL TO PREVENT MENTAL RETARDATION AND RELATED DISABILITIES

Speakers

Summit opening
Albert L. Anderson, D.D.S.
Vice Chairperson
President's Committee on Mental Retardation
San Diego, California

Opening Statement
William Kerby Hummer, M.D.
Chairperson
Prevention Subcommittee
President's Committee on Mental Retardation
Santa Monica, California

Statement of Occasion... "The Challenge"
Hugo Moser, M.D.
Director
Center for Research on Mental Retardation and Related Aspects of Human Development
Baltimore, Maryland

Keynote Address
Duane Alexander, M.D.
Director
National Institute of Child Health and Human Development
U.S. Department of Health and Human Services
Bethesda, Maryland

Luncheon Address
Louis W. Sullivan, M.D.
Secretary
U.S. Department of Health and Human Services
Washington, D.C.

Exemplary State Planning to Prevent Mental Retardation and Related Disabilities Associated with Socioeconomic Conditions
George Schmidt, Ph.D.
Program Manager
Health and Rehabilitative Services
Tallahassee, Florida

<u>Speakers</u> - (Con't)

Roger Chapman
Program Manager
Disability Prevention Program
Department of Public Health
Des Moines, Iowa

Deborah E. Cohen, Ph.D.
Director office for Prevention of Mental Retardation and Developmental Disabilities
Department of Human Services
Trenton, New Jersey

Raymond Peterson, M.D.
Director
San Diego Regional Center for Developmentally Disabled Persons, Inc.
San Diego, California

Presenters of Papers

Impact of the "New Morbidity" on Epidemiological Rates

Godfrey Oakley, M.D.
Centers for Disease Control
U.S. Department of Health and Human Services
Atlanta, Georgia

Healthy People 2000 Objectives for the Nation

Ashley A. Files
Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services
Washington, D.C.

A National Prevention Agenda

Allen Crocker, M.D.
Children's Hospital Medical Center
Boston, Massachusetts

Preventing the "New Morbidity": A National Plan of Action

Alfred Baumeister, Ph.D.
Peabody College, Vanderbilt University
Nashville, Tennessee

Preventing Mental Retardation and Related Disabilities Associated with Socioeconomic Conditions

Edward Zigler, Ph.D.
Yale University
New Haven, Connecticut

The Role of Developmental Disabilities Councils and Agencies in Prevention Planning

Deborah McFadden
Commissioner
Administration on Developmental Disabilities
U.S. Department of Health and Human Services
Washington, D.C.

Presenters of Papers - (Con't)

Prevention Initiatives of the Administration on Children, Youth and Families to Meet the Needs of Socioeconomically Disadvantaged Mothers and Children

Wade Horn, Ph.D. Commissioner
Administration on Children, Youth and Families
U.S. Department of Health and Human Services
Washington D.C.

Support Services of the Maternal and Child Health Bureau in Prevention

Vince L. Hutchins, M.D.
Acting Director
Maternal and Child Health Bureau
U.S. Department of Health and Human Services
Bethesda, Maryland

Social Security Initiatives that Reduce Children's Morbidity

Gwendolyn King
Commissioner
Social Security Administration
U.S. Department of Health and Human Services
Washington, D.C.

Rehabilitation Services Administration Options for Interagency Prevention Initiatives

Nell Carney
Commissioner
Rehabilitation Services Administration
Office of Special Education and Rehabilitative Services
U.S. Department of Education
Washington, D.C.

Ameliorating the Effects of Mental Retardation Related Disabilities in Aged Adults

Joyce Berry, Ph.D.
Commissioner
Administration on Aging
U.S. Department of Health and Human Services
Washington, D.C.

Presenters of Papers - (Con't)

National Institute on Disability and Rehabilitation Research Interagency Collaboration and Research in Mental Retardation

William Graves, Ph.D. Director
National Institute on Disability and Rehabilitation Research
U.S. Department of Education
Washington, D.C.

Provisions of the Education of the Handicapped Act -- Part H

Michael E. Vader
Deputy Assistant Secretary
Office of Special Education and Rehabilitative Services
U.S. Department of Education
Washington, D.C.

Special Education Service Delivery for a Changing Population of Students with Disabilities

Judy Schrag, Ph.D. Director
Office of Special Education Programs
U.S. Department of Education
Washington, D.C.

Substance Abuse and Teratogenic Factors

Judy Howard, M.D.
Professor of Clinical Pediatrics
University of California at Los Angeles
Los Angeles, California

Professional Training to Meet the Needs of Mothers and Children with HIV Infection and AIDS

Herbert J. Cohen, M.D.
Professor of Pediatrics and Rehabilitation Medicine Albert Einstein College of Medicine
Bronx, New York

Report of the World Summit on Children

James M. Sherry, M.D., Ph.D.
UNICEF
New York, New York

Return Us the Children--- Societal Prerequisites

Travis Thompson, Ph.D.
University of Minnesota
Minneapolis, Minnesota

Moderators

Panel I What We Can and Must Do

Christopher DeGraw, M.D.
Coordinator, Children and School Programs
Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services
Washington, D.C.

Panel II Preventing the "New Morbidity" ... Improving Options for Mothers and Children

M. Doreen Croser
Executive Director American Association on Mental Retardation
Washington, D.C.

Panel-III Preventing the "New Morbidity" ...
Cooperative Multi-agency Approaches and Options

James Harrell
Deputy Director
Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services
Washington, D.C.

Panel IV Improving the Health Status of Children

Rudolph Hormuth
Specialist in Services to Mentally Retarded Children
Maternal and Child Health Bureau
Public Health Service
U.S. Department of Health and Human Services
Rockville, Maryland

Panel V Exemplary State Planning to Prevent Mental Retardation and Related Disabilities
Associated with Socio-economic Conditions

Michael J. Adams, Jr., M.D.
Medical Epidemiologist
Division of Birth Defects and Developmental Disabilities
Center for Environmental Health and Injury Control, Centers for Disease Control
Public Health Service
U.S. Department of Health and Human Services
Atlanta, Georgia

Moderators – (Cont)

Closing Plenary

Fred Krause
Director
Rehabilitation and Health Services
Partners of the Americas
Washington D.C.

WorkGroup Leaders

Work Group I

Application of the "New Morbidity Model" to Comprehensive State Planning

Alfred Baumeister, Ph.D.
Director
John F. Kennedy Center for Research on Education and Human Development
Peabody College, Vanderbilt University
Nashville, Tennessee

Work Group II

The Role of the State and Federal Government in Facilitating Comprehensive State Planning

James Harrell
Deputy Director
Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services
Washington, D.C.

Work Group III

Strategies for Addressing Epidemiological Needs, Concerns, and Interests

Godfrey Oakley, M.D.
Director
Division of Birth Defects and Developmental Disabilities
Center for Disease Control
U.S. Department of Health and Human Services
Atlanta, Georgia

Work Group IV

Successful Planning of Constituency Group, Interagency and/or Intra-agency Initiatives that Support Comprehensive Planning

Sony Oppenheimer, M.D.
Director, Myelomeningocele Program
Assistant Director, Cerebral Dysfunction Program and Neural Birth Defects Program
Cincinnati Center for Developmental Disabilities
Cincinnati, Ohio

Work Group Leaders – (Con't)

Work Group V

Practical Approaches to the Formulation and Endorsement of National Prevention Policy
Allen Crocker, M.D.
Director
Developmental Evaluation Clinic
Children's Hospital Medical Center
Boston, Massachusetts

Exhibitors

"Prevention 1995 - California's Future" Department of Development Services Sacramento, California	Mary Lou Hickman, M.D.
Elwyn, Inc. Elwyn, Pennsylvania	Carol Cherrix
"Forging a New Era" National Association of Developmental Disabilities Council Washington, D.C.	Susan Ames Zierman
National Association for the Dually Kingston, New York	Michelle Jordan Diagnosed
National Institute on Disability Rehabilitation Research Washington, D.C.	James Doherty
North Carolina Office for Prevention Division of Maternal and Child Health Raleigh, North Carolina	Donna Scandlin
Office for Prevention of Mental Retardation and Developmental Disabilities North Brunswick, New Jersey	Glenna Gundan
"Outreach for Parents" National Parent Network on Disabilities Alexandria, Virginia	Patty Smith
"Prevention Education Exhibit" Retarded Citizens/Atlanta Atlanta, Georgia	Martha Towle
Social Security Administration Baltimore, Maryland	Lorraine Gunning
The National Center for Education in Maternal and Child Health Washington, D.C.	Maureen R. Seller