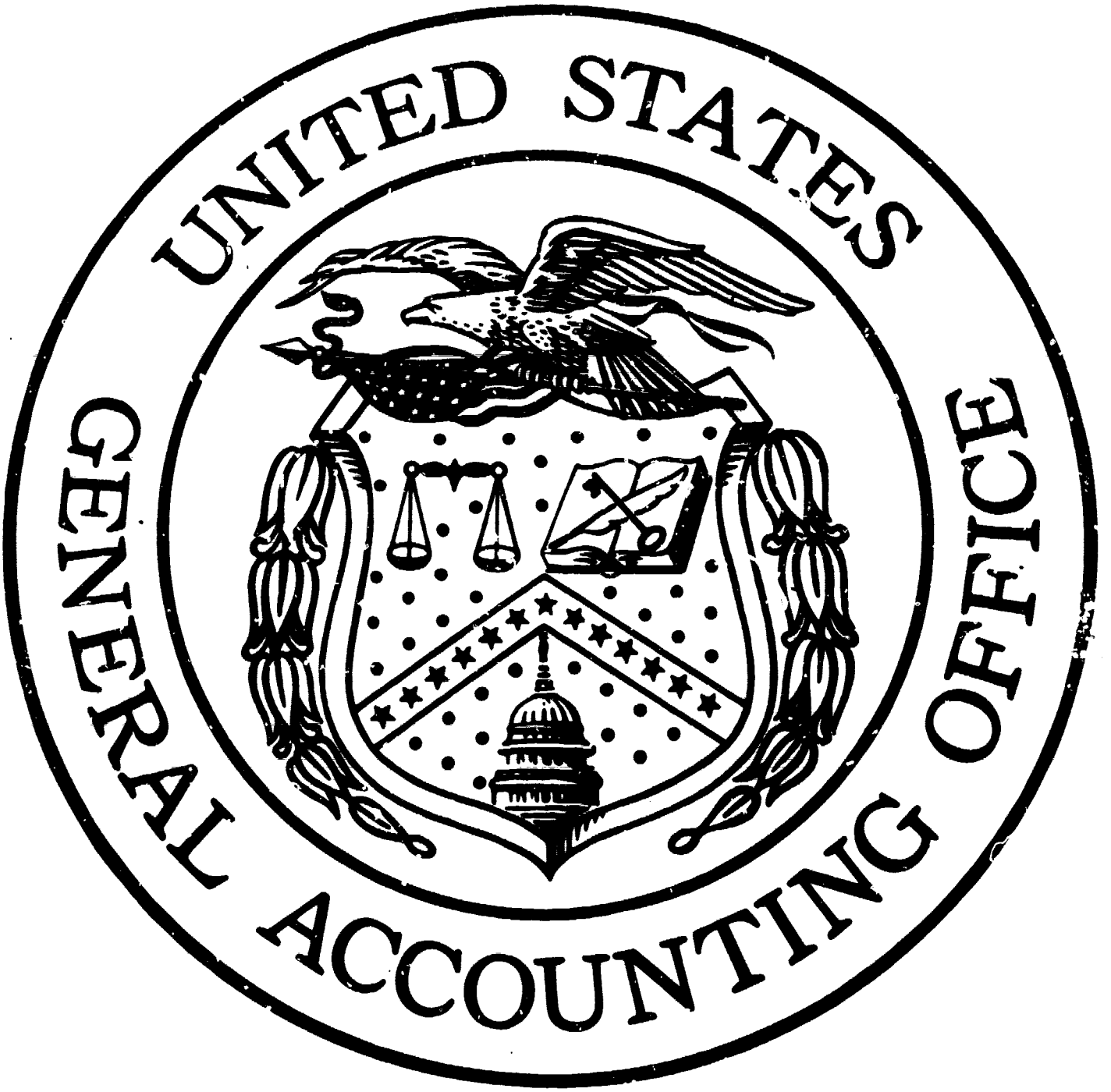
2 OF 2



intensive stimulation and education intervention can minimize developmental problems normally presented by high-risk children when they attain school age.

ONGOING PROGRAMS HAVE NOT BEEN SYSTEMATIZED

In the States reviewed, we identified many programs which included parent education and/or early intervention. However, information on the results or effectiveness of these programs was not being centrally or systematically collected and evaluated. Most State health and education officials we contacted were unaware of the extent, scope, or content of programs in their States. For example, we identified several programs in Missouri that included education on childhood development, but State officials had no information on the scope, content, or design of the programs and told us that we would have to obtain such information from the projects themselves. Although we found several programs and projects in Missouri which appeared to include early intervention, the director of the Missouri division of health stated that the adequacy of the intervention programs is still to be determined.

The director of special education projects for Missouri told us that the department of elementary and secondary education provided funds to local school districts to operate programs for 3 and 4 year olds. However, information concerning the programs' format was not required to be submitted to the State so he had no information on individual program content; he did not even have a list of the districts that had such projects.

In California, there were several private and publicly supported programs designed to enhance early childhood development. California's department of education operates several programs directed at parent education and early childhood development including: Early Childhood Education Outreach, preschool programs, the School Age Parenting and Infant Development Program, and the Child Development Programs. However, education officials said that no standards had been set up or evaluations done to measure their impact. Also, since the programs of the department of education were administered at the school district level, and since each school district was autonomous, the individual program approaches varied.

One California health official said his department had been reluctant to implement widespread intervention programs

because they were not yet convinced of the programs' merits. He cited the inconclusiveness of the developmental testing methods used, especially testing based solely on intelligence quotient measurement. An additional drawback he saw was that the state-of-the-art of child development and early intervention techniques is unclear and experts in the field disagree on proper intervention methods.

In Georgia, the State director of physical health told us that very little was being done to educate parents and to identify and intervene with high-risk infants. Other State and HEW regional officials interviewed said they believed there were such programs operating in the State, but they could not identify them. For example, Region IV's Coordinator for Education and Community Services said that there were various education programs to help parents properly develop their children, but they varied by State and State officials would have to be contacted to obtain specific information.

We identified several programs in Georgia which appeared to include education on childhood development, such as the Parent Education Demonstration Projects funded by the Office of Education, and programs offered through State-supported child development centers, but State officials had not collected or evaluated information on the programs' design or what they included.

THE NEED FOR FEDERAL EVALUATION OF PREVENTION TECHNIQUES

Several Federal studies have been made to identify research and intervention programs throughout the country. One study completed under an HEW contract in 1972 to assess the delivery of early intervention programs to potentially retarded children identified more than 40 longitudinal intervention research programs for high-risk children.

In 1974, the National Leadership Institute/Teacher Education at the University of Connecticut completed a survey to determine what programs for children under 3 years of age were operating or proposed. Information was solicited from several sources, including State departments of education, State offices of child development, and early education program directors. A total of 53 ongoing and proposed programs were identified operating at 116 sites and involving about 19,000 children and their families. Additionally, 8 universities and 23 community colleges were involved in infant and toddler research and service programs.

The Office of Child Development, the Office of Education, and the National Institute of Mental Health jointly sponsored a program to help teenage boys and girls prepare for parenthood through learning about child development and working with young children. As part of the program, a workstudy curriculum in child development was developed for secondary school students. The course was tested in 234 schools during the 1973-74 school year and in 1975 was being started in about 1,000 schools, universities, and other organizations throughout the country.

Aside from these efforts, no single agency within HEW assumed responsibility for systematically evaluating the results of such programs or for seeing that effective techniques are implemented. In 1972, an HEW contractor reported on the status and results of intervention research projects funded from a variety of private and Federal sources including the Office of Education, the Office of Child Development, and the National Institute of Mental Health. The report stated that (1) there is no centralized system to guide and orchestrate the various longitudinal intervention research activities being conducted, (2) in most respects, the area is actually understudied in light of the research results obtained and the promise they show, especially with very young children with moderately low intelligence quotient scores, and (3) no significant studies were being conducted to evaluate the social and cost benefits of intervention with potentially retarded preschool children.

A report prepared by the National Institute of Child Health and Human Development for presentation to the National Advisory Child Health and Human Development Council in 1973 stated:

> "Too little attention has been given to the damaged and at risk infant, and we need to know much more about the interaction effects operating in his early development as building blocks to intervention programs. In particular, we need to systematize this work and make it at once whole with objectives of our goal-optimal intervention for the damaged and risk infant and child."

The outcome of the Milwaukee Project is an example. After 10 years of operation, Federal funding of the study lapsed. No systematic evaluation has been made of the study's results to determine if the techniques used are effective or could be implemented in other Federal programs. Rehabilitation Services Administration officials believed the study results were of great value and that it should be continued, but attempts by

that agency and PCMR to have other HEW programs continue funding of that or similar projects have been unsuccessful.

A Rehabilitation Services Administration official told us that agency had not continued that or similar projects because it was outside the scope of its responsibility. No clearcut reasons could be given as to why other agencies had not picked up project funding except that PCMR had apparently been unable to generate enough interest in it and no other agency felt that the project fell directly under its responsibility.

An October 1975 seminar, jointly sponsored by the University of Wisconsin, PCMR, the National Association for Retarded Citizens, and HEW, pointed to a need to identify the most effective early childhood intervention techniques, coordinate researchers and practitioners to solidify research data and implement research results, and implement evaluation and assessment systems.

CONCLUSIONS

Since the majority of the incidence of retardation is attributable to adverse early childhood experiences, any effective prevention strategy must address these causes. Although many studies and projects have been undertaken in this area, HEW has not established a strategy or fixed responsibility for identifying, evaluating, and implementing the most effective and cost beneficial parent education and early intervention techniques or for coordinating the work of researchers and practitioners.

RECOMMENDATIONS

We recommend that the Secretary of HEW:

--Fix responsibility for (1) collecting results of studies of parenting education and early intervention techniques and programs that have used these preventive measures and (2) evaluating their success.

--Identify (1) areas in most need of study and (2) most effective and cost beneficial methods of prevention.

--Disseminate information developed from evaluation of studies and programs to other Federal and State agencies for consideration in implementing their programs.

AGENCY COMMENTS AND OUR EVALUATION

HEW in commenting on a draft of this report did not comment on our specific recommendations but advised us that the issues will be addressed when the specific focal point in the Office of the Assistant Secretary for Health is designated.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
OFFICE OF THE SECRETARY
WASHINGTON, D.C. 20201

JUL 25 1977

Mr. Gregory J. Ahart
Director, Human Resources
Division
United States General
Accounting Office
Washington, D.C. 20548

Dear Mr. Ahart:

The Secretary asked that I respond to your request for our comments on your draft report entitled, "Preventing Mental Retardation: More Can be Done." The enclosed comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

We appreciate the opportunity to comment on this draft report before its publication.

Sincerely yours,

Thomas D. Morris
Inspector General

Enclosure

COMMENTS OF THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE ON THE COMPTROLLER GENERAL'S DRAFT REPORT TO THE CONGRESS OF THE UNITED STATES ENTITLED "PREVENTING MENTAL RETARDATION: MORE CAN BE DONE"

General Comments

We are in general agreement with the draft report.

We find the conclusions contained in the draft report valid and the recommendations worthy of implementation. Further, it reflects an approach which has characterized the Department's activities since the President's Panel on Mental Retardation reported its conclusions in 1962.

Since that time, the Department has focused its efforts on those selected causes of mental retardation identified in the report, e.g., metabolic disorders, prematurity and low birth weight, chromosome abnormalities, rubella and measles, lead poisoning, Rh hemolytic diseases, and early childhood experiences. It also supported research directed to a better understanding of other factors associated with mental retardation (MR). The GAO report is inadequate in its attention to research programs and fails to recognize the necessity for research to reduce the incidence of mental retardation. A limited description of the Department's research program underplays its significance in attacking the causes of mental retardation. Research is needed in the areas of genetics, abnormal fetal growth, birth trauma, prenatal infection, malnutrition (all biologic causes of mental retardation), and psychosocial deprivation (80% of mental retardation stems from the influence of an unfavorable environment). In addition, within the framework of the existing service delivery system, current knowledge and techniques on how preventive service delivery can be extended to a larger segment of the risk population, and how the delivery can be made more effective and efficient through leadership and coordination have been addressed by the Department. HEW delivers services only to a small minority of the at-risk population. If the goal of reducing MR by 50% is to be achieved, the private sector must be involved along with public health programs.

While the draft report is clearly focused on a preventive effort related to known biomedical causes, Chapter I of the report tends to somewhat confuse the focus by addressing the broad problem of mental retardation and to some extent leading to an expectation that subsequent sections of the report might also address some of the issues of research, training, or the sociocultural aspects of mental retardation.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Designate a focal point in HEW to implement a national prevention strategy, monitor and coordinate the efforts of the various HEW agencies and offices, and develop a method of determining the progress being made in reaching the goal.

APPENDIX I

2. Designate prevention of mental retardation as an objective in HEW's operational planning system.

DEPARTMENTAL COMMENTS

1. We concur. The focal point for the Department will be in the Office of the Assistant Secretary for Health (OASH). The specific office within OASH will be designated by the Assistant Secretary for Health.

2. We will consider including the prevention of mental retardation as an objective if the operational planning system is continued. Whether the departmental system is continued or not, the relevant issues will be monitored by the agency tracking system.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW help improve newborn screening by:

1. Determining what is needed to improve the coverage and effectiveness of newborn screening programs and assisting States in improving their programs.

2. Encouraging and supporting expansion of newborn screening to include other treatable metabolic disorders in addition to PKU.

3. Encouraging and assisting States to cooperate in establishing cost-effective regionalized metabolic screening programs.

Department Comments

1. We concur. The PHS Child Health Strategy addresses those issues, as do the implementation plan for the Genetic Diseases Act and ongoing activities described in response to the next two recommendations. In a few States, hospitals still have the option of using private laboratories and reporting is difficult. Some States, for example, with only 6,000 births per year and whose laboratory capacity limits their testing to the simple Guthrie procedure for Phenylketonuria, find it uneconomical to expand their screening for additional conditions, such as hypothyroidism, which would involve the purchase of additional expensive equipment. Many States hesitate to include other conditions in their screening

programs, such as Maple Syrup Urine Disease, because of a concern about their ability to provide adequate treatment services for those infants that might be detected (i.e., available genetic centers to manage and monitor the infant and to purchase and provide the amino acid dietary products).

2. We concur. This encouragement and support takes several forms, such as technical assistance to State Health Department laboratories as to how the same blood spot on filter paper could be used to test for multiple conditions, providing some additional equipment to automate procedures, developing guidance material on laboratory screening procedures, treatment, and management. Additional support for the genetic centers (generally genetic units at medical centers to which States refer positive screening results for management) would considerably encourage States to expand their screening efforts if they could be assured that these centers they have designated could handle the increased load. At the moment, there is considerable interest in hypothyroid screening for which effective treatment and management may be comparatively simple compared to the other conditions. The full implementation of Title IV of the Genetic Diseases Act by the Bureau of Community Health Services should enhance the capability of the genetic centers and encourage a number of States to expand their newborn screening.

3. We concur. Regional Newborn Screening Laboratories facilitate quality control and permit economies of scale. Consequently, they are the most cost effective approach. Two major Regional Newborn Screening Laboratories have been established with the assistance of the Maternal and Child Health Programs, BCHS. The Massachusetts State Health Department Laboratory by contractual agreement is screening all of the newborn samples from the New England States, except Connecticut, for five different conditions. The Oregon State Health Department has similar arrangements with the States in the northwest. At the moment, California is in the process of setting up three regional laboratories for the State. Ohio and North Carolina are interested when start up costs are available. Other States are being encouraged to participate in regional systems through HEW-funded university affiliated centers and genetics projects.

GAO RECOMMENDATIONS

To be able to establish priorities for the allocation of prenatal care funds in the most effective manner and to the areas of greatest need, GAO recommends that the Secretary of HEW direct the Bureau of Community Health Services to:

1. Evaluate the State procedures used to determine needs for prenatal care services and insure that State plans outline a clear strategy of how to reach the population in greatest need.

(See GAO note on p. 96.)

Department Comments

1. We concur. Delegation of responsibility for Title V of the Social Security Act to BCHS has included the responsibilities contained in the recommendation. The maternity and infant care projects program, established by the Maternal and Child Health Programs, was targeted on high risk populations (pregnant women in low income areas who had previously received little or no prenatal care). While these programs provided such care and demonstrated an ability to decrease the infant mortality, they only provided for follow-up of the newborn infant for one year and hence were never able to document outcome in terms of the ultimate goal of reducing mental retardation. Based on a State-by-State assessment of high infant mortality and morbidity distribution, BCHS has initiated Statewide Improved Pregnancy Outcome projects in 9 states. An additional 9 are projected for fiscal year 1977. HSA is aware that in many States the unmet need for prenatal care has not been sufficiently analyzed (pp. 44-47). In fact, the assessment of health service needs of mothers and children in all States is an element of HSA's Child Health Strategy for fiscal year 1978-1982.

(See GAO note on p. 96.)

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Direct federally supported family planning programs to include, as a routine part of their services, screening for individuals who are "high risk" for genetic disorders and refer such individuals to diagnostic and counseling services.

2. Monitor the demand on existing genetic resources created by outreach and develop strategies for increasing resources as needed.

3. Explore how other Federal programs could better be used to provide genetic screening and services.

Department Comment

1. We concur, in principle, but can not mandate universal screening until more capacity for effective screening and counseling is available. Family Planning Program Guidelines recommend these as clinic services where available.

   The demand on existing genetic resources at present exceeds their capacity. It is estimated, for example, that only 10,000 prenatal diagnoses were provided by existing genetic resources in 1976. Twenty genetic centers provided almost half of these evaluations.

2. We concur. The continued monitoring of the demand on existing genetic resources is most important in implementing these recommendations to assure that the demands generated by any outreach and additional screening can be dealt with by the centers. Both the Child Health Strategy and the Genetic Diseases Implementation Plan stress State-wide networks with the State Health Department playing the key role in establishing linkages between screening and provider programs.

3. We concur. Now that the focal point has been established, it will be possible to work out a mechanism to include these activities in other Federal programs.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Examine the alternative of expanding the Center for Disease Control support of State vaccination programs, or making arrangements between CDC and the Social and Rehabilitation Service that will enable EPSDT to more effectively support national and State immunization activities.

2. Expand EPSDT requirements to specifically require screening for immunization status and reporting of the number of screened and the number immunized.

3. Require Head Start projects to develop data on the results of their immunization screening.

4. Require federally funded family planning and other appropriate programs to include rubella susceptibility testing and immunizations,

APPENDIX I

where appropriate, among their routine services.

Department Comments

We concur. The draft proposed revision to the EPSDT Penalty Regulation will require that the immunization status of each Medicaid recipient be determined at the time the screening test is performed. Revisions to current reporting requirements are in process and include reporting on inadequate immunization status found through screening.

The Department has proposed to Congress on April 25, 1977 legislation to convert EPSDT to a Comprehensive Health Assessments and Primary Care for Children Initiative which will address these issues. This has been introduced as H.R. 6706 and S. 1392.

References in the draft (pp. 63-64) to the United States Immunization Survey should be reviewed. CDC has completed an evaluation of this survey; changes which the evaluation report recommended to improve accuracy have been approved and the Bureau of the Census, which conducts the survey for CDC, has implemented the changes. More aggressive vaccination efforts are needed and the Department is currently planning for them to include better coordination at a local level of the CDC effort with EPSDT, Head Start, Child Find, and the Maternal and Child Health delivery system.

While the recommendation that the federally funded family planning program be required to include rubella susceptability testing is generally compatible with improved prevention of Rh disease, the usefulness of Rh typing in family planning clinics and in premarital serologics remains to be shown. The critical time to identify the Rh negative woman is prior to birth of her child or at abortion. Screening at other times should be shown to be cost effective before adoption as a recommended public health measure.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Provide guidance to the States on how best to use their EPSDT program to identify areas needing screening for lead poisoning; encourage the States to embark upon aggressive lead screening efforts; and support expansion of public and physician education on the problem of lead poisoning.

2. Require reporting under EPSDT of the number of individuals screened for lead poisoning as well as the number referred for treatment.

APPENDIX I

3. Require HEW agencies that are screening for lead poisoning to report on the results of screening to aid in identifying problem areas.

4. Consider having CDC develop a surveillance system to analyze the problem at the national level.

Department Comments

We concur in part. In addition to recommending improvements in the EPSDT program through changes in the enabling legislation, the Department is reviewing current program operations to achieve optimum performance. These issues are being addressed in that context.

An Information Memorandum on lead poisoning is being prepared by EPSDT staff, which provides information on problems, risk, and new technology in testing for lead poisoning called the FEP (Free erythrocyte protoporphyrin). This test's low cost should encourage the States to use it. A copy of the CDC pamphlet titled, Increased Lead Absorption and Lead Poisoning in Young Children, dated March 1975, will be attached to the Information Memorandum. The pamphlet provides technical and specific information on methods used to screen, diagnose, treat and follow-up on children with increased lead absorption and lead poisoning. On page 1 of this CDC document, definitions of "Lead Poisoning", "Undue or Increased" "Lead Absorption" and "Toxicity" used by the Department are set forth. We recommend that GAO use these definitions in the body of this chapter in order to clarify the recommendations.

Reporting requirements in the recommendation are being considered in the revisions being made to the current reporting requirements for EPSDT. The age group most vulnerable to the ill effects of excess lead, 18 months to 3 years, is also the group most likely to suffer from iron deficiency anemia (up to 40% in lower socio-economic groups). Hence, for every suspicious case detected by protoporphyrin measurements, it will be necessary to rule out iron deficiency as a cause for high protoporphyrin levels while remembering that both may co-exist.

Preliminary analysis of the problem by CDC documents lead in dust as one of the current major problems. A variety of sources, such as lead based paint on the exterior of buildings, automobile emissions, fumes from industrial plants, etc. all contribute to this airborne lead. While the ideal long range solution of the problems of lead poisoning would be elimination of all environmental sources of lead, the more immediate public health approach requires a continuing effort at screening detection and correction of episodic problems.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Instruct CDC to determine if the incidence of Rh disease is lower in States having mechanisms for monitoring Rh disease and immuno-

globulin use. If such surveillance mechanisms are effective, encourage States to develop comprehensive systems to: test all pregnant women for Rh incompatibility, report incidence of Rh hemolytic disease and use of Rh immunoglobulin to CDC, thereby establishing a national program for monitoring the incidence of the disease.

2. Require federally supported family planning programs to include Rh blood typing as a routine part of family planning services.

3. Encourage Rh testing in all deliveries, miscarriages, or abortions paid for with HEW funds and providing of immunoglobulin to women who need it.

Department Comments

1. We concur. CDC is involved in the monitoring and surveillance of Rh disease. It offers consultation to States upon request by helping them determine the nature of the problem and offering possible solutions.

2. We concur. Rh type should be considered an essential component of every girl's personal health knowledge. Rh typing could be provided through several Federal programs as are immunizations currently. If a client has not been typed and presents herself at a family planning clinic, this will be included as a routine part of family planning services.

3. We concur. Programs supported through Title V funds are encouraged to include prevention of Rh disease in all programs. Title XIX standards are set by States and while the Department urges comprehensive service availability, the decision ultimately rests with the States.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Fix responsibility for (1) collecting results of studies of parenting education and early intervention techniques and programs that have used these preventive measures and (2) evaluating their success.

2. Identify (1) the areas in most need of study and (2) the most effective and cost beneficial methods of prevention.

3. Disseminate information developed from evaluation of studies and programs to other Federal and State agencies for consideration in implementing their programs.

Department Comments

These issues will be addressed when the specific focal point in OASH is designated.

GAO note: Deleted material refers to matters not discussed in this final report. Page references in this appendix may not correspond to page numbers in the final report.

APPENDIX II

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
WASHINGTON, D.C. 20201

February 15, 1977

Mr. Gregory Ahart, Director
Human Resources Division
United States General
Accounting Office
441 G Street, N.W.
Room 6864
Washington, D.C. 20548

Dear Mr. Ahart:

The President's Committee on Mental Retardation commends you on the recent report "Preventing Mental Retardation: More Can Be Done." The report was the subject of a meeting of our Task Force on Biomedical Prevention which included representatives of the American Association on Mental Deficiency, and the National Association for Retarded Citizens.

The Task Force was thus able to respond verbally to Mr. Frank Ackley of your staff.

In addition we have shared the report with all Committee Members as a way of keeping them informed on this vital subject.

The GAO staff members who worked on this were "quick studies" who, coming from a discipline outside the realm of mental retardation, were able to absorb both the facts and the issues and arrive at sound recommendations.

We cannot emphasize too much that prevention of mental retardation is both cost beneficial and cost effective and would underscore the report's emphasis on this area.

While we recognize that it was not possible to cover each and every one of the more than 200 causes of mental retardation the report does speak to the categories which group the many specific disorders causing mental retardation, and is consistant with the AAMD manual on terminology and classification.

APPENDIX II

PCMR will be meeting with representatives of each of the Departments of Federal Government in order that each Department may identify those programs they will initiate, or expand in order to make significant contributions to reducing the incidence of mental retardation.

PCMR will also keep up to date on DHEW's progress in prevention.

We concur with the recommendations of the report, and thank you for the opportunity to review this document.

Sincerely,

Fred J. Krause
Executive Director

Allen R. Menefee
Assistant Director, Program

APPENDIX III

PRINCIPAL HEW OFFICIALS RESPONSIBLE FOR ACTIVITIES DISCUSSED IN THIS REPORT

	Tenure of office	
	From	To
SECRETARY OF HEW:		
Joseph A. Califano, Jr.	Jan. 1977	Present
David Mathews	Aug. 1975	Jan. 1977
Caspar W. Weinberger	Feb. 1973	Aug. 1975
Frank C. Carlucci (acting)	Jan. 1973	Feb. 1973
Elliot L. Richardson	June 1970	Jan. 1973
ASSISTANT SECRETARY FOR HEALTH:		
Julius Richmond	July 1977	Present
James F. Dickson III (acting)	Jan. 1977	July 1977
Theodore Cooper	May 1975	Jan. 1977
Theodore Cooper (acting)	Feb. 1975	Apr. 1975
Charles C. Edwards	Mar. 1973	Jan. 1975
Richard L. Seggel (acting)	Dec. 1972	Mar. 1973
Merlin K. Duval, Jr.	July 1971	Dec. 1972
ASSISTANT SECRETARY FOR HUMAN DEVELOPMENT:		
Arabella Martinez	Jan. 1977	Present
Stanley B. Thomas, Jr.	Aug. 1973	Jan. 1977
Stanley B. Thomas, Jr. (acting)	Apr. 1973	Aug. 1973
ADMINISTRATOR, SOCIAL AND REHABILITATION SERVICE:		
Don I. Wortman (acting)	Jan. 1977	Mar. 1977
Robert Fulton	June 1976	Jan. 1977
Don I. Wortman (acting)	Jan. 1976	June 1976
John A. Svahn (acting)	June 1975	Jan. 1976
James S. Dwight, Jr.	June 1973	June 1975
Francis D. DeGeorge (acting)	May 1973	June 1973
Philip J. Rutledge (acting)	Feb. 1973	May 1973
John D. Twiname	Mar. 1970	Feb. 1973
ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION:		
Robert A. Derzon	Apr. 1977	Present
Don I. Wortman (acting)	Mar. 1977	Apr. 1977

10217