REPORT OF THE COMMITTEE TO STUDY REVENTABLE CAUSES OF MENTAL RETARDATION

REPORTED TO

THE GOVERNOR

AND

GENERAL ASSEMBLY OF VIRGINIA

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REPORT OF THE COMMITTEE TO STUDY PREVENTABLE CAUSES OF MENTAL RETARDATION

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Report of the Committee to Study

Preventable Causes of Mental Retardation

to

The Governor and the General Assembly of Virginia

Richmond, Virginia

November 1, 1975

TO: The Honorable Mills E. Godwin, Jr.
Governor of Virginia

and

The General Assembly of Virginia

The General Assembly at its regular session of 1975 enacted Resolution No. 18 directing the State Mental Health and Mental Retardation Professional Advisory Board to make a study and report upon the need and feasibility of programs directed toward the prevention of medical causes of mental retardation.

The Board, having completed its work, submits this report:

PREFACE

Resolution 18 in directing the medical causes of mental retardation limited the Board to this one aspect of a problem of which medical causes represent about 15%. In preparing this report the Board wishes to note that there are other significant causes of retardation with which this report does not attempt to deal. Specifically, the behavioral consequences of low stimulous input and its effect upon development must be taken into consideration in any comprehensive study of mental retardation and may well contribute as well to the medical factors with which this report does deal. We mention this lest there be misconceptions that the measures recommended in this report might wipe out the total problem. This, of course, would not be true.

The report represents several meetings of the Committee as a whole, deliberation of several subcommittees, and the individual input of a number of committee members. The final draft was reviewed and edited by the membe of the State Mental Health and Mental Retardation Professional Advisory Board individually and in concert. There was some delay in the preparation of the report since the first chairman of the committee was forced to resign when he left Virginia midway through the deliberations.

The matter of a central registry was considered by the Board as directed in Resolution 18. Recognizing that such a registry could be valuable, we were also aware that it presents issues of invasion of privacy with significant ethical, moral, and legal overtones which are complicated and controversial. The Board felt it advisable that the decision about it should be at the Policy rather than Advisory level and that it be considered along with the concept of registries concerning other health and social conditions.

With these preparatory comments, we proceed with our report.

William H. Young, Jr., M. D.
Chairman
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INTRODUCTION

Mental retardation is "significantly sub-average general intellectual function with defects in adaptive behavior, manifested during the developmental period". There are more than 200 known causes of mental retardation. Although currently it is not possible to prevent some persons from being mentally retarded, it is now both feasible and necessary to diminish its incidence. President Nixon noted that if all existing knowledge in our field was wholly applied and utilized, we might prevent half of all new cases of mental retardation. He challenged Americans to join with him in his pledge "to reduce by half, the occurrence of mental retardation in the United States before the end of this century". If we are to meet this challenge, we must grasp and draw fully upon the strengths of our private and public agencies. Persons may have mild, moderate or profound mental retardation and they, their families and society, suffer in proportion to the nature and severity of the intellectual impairments.

It is essential that the Commonwealth of Virginia actively undertake programs to prevent mental retardation in order to be properly responsible to its citizens, to fulfill its humanitarian aim to reduce suffering and improve the quality of life and to relieve its taxpayers of the financial drain upon public monies which each unnecessary instance of mental retardation now necessitates.

Effective reduction of the frequency of mental retardation will require cooperation and coordination of state agencies, local agencies, physicians, social welfare persons, educators, and others. Mental retardation presents a major social, educational, health and economic problem and intimately affects one out of every ten persons in the Commonwealth of Virginia. Mental retardation creates problems currently dealt with by persons and programs in the Departments of Health, Mental Health and Mental Retardation, Welfare, Education, Division of Vocational Rehabilitation, and other state services. The fragmentation of responsibility hinders comprehensive planning and contributes to suboptimal coordination and efficiency. We urge the Governor to develop a Coordinator of Programs for Prevention of Mental Retardation to facilitate cooperative efforts, develop new programs, gather information and evaluate existing programs.

The Health Department already has the knowledge and ability to prevent many cases of mental retardation. It is tragically understaffed and under funded. Extension of public health programs to reduce mental retardation is one of the strongest recommendations of this Committee. Mental retardation is very expensive. It is false economy to attempt to save money by being irresponsible to public health, while at the same time, necessarily spending tax dollars to take care of the problems created by poor preventive medicine. Some illustrative cost figures are included on Appendix A, page 32 and throughout this report.

Currently, the citizens of the Commonwealth of Virginia are poorly informed about means for reducing mental retardation. It is important that every prospective family have access to appropriate information and guidance in the planning, nurture and protection of its members. Families may proceed with greater caution when provided with information such as:

> Limiting pregnancies to ages 18 through 35 would eliminate a vast amount of mental retardation, including two-thirds of the cases of Down's Syndrome (Mongolism).
>
> Diabetes is dangerous to the unforn infant with a high risk of brain damage. The risk is so severe that one out of four babies die in the womb if the mother is not under excellent medical supervision.
>
> Prior to recently improved management and preventive techniques up to 10,000 babies per year were stillborn due to Rh blood disease. 20,000 now are at risk for developmental disabilities, some of which can be detected before birth.
>
> Through early diagnosis and treatment, mental retardation can be prevented in newborns with PKU and similar conditions.

The Department of Mental Health and Mental Retardation has a significant opportunity and responsibility to inform the citizens of Virginia about mental retardation. The Department should undertake a major campaign of publicity and education to create a climate in which positive steps can be taken. Extensive, continuing effort must be undertaken to educate laymen, physicians, legislators, educators, social welfare persons, school children, current and prospective parents and others. Publicity and education are the primary requirements to decrease the incidence of mental retardation. We feel that adequate information will lead to increased demand for services which, in turn, will justify increased expenditures of the funds which are mandatory to reduce mental retardation and save the state money in so doing.

The grief, loss of human potential and cost of this affliction is untold. Much of it can be prevented; the effects of all of it can be reduced. Let the Commonwealth of Virginia apply that which is known and begin now to reach for that which is not yet understood.

RECOMMENDATIONS

General Recommendations

1. Educate laymen, school children, physicians, social welfare personnel and public as to:

    a. Resources available
    b. Resources needed
    c. The need to prevent mental retardation

    Education is a major responsibility of the Department of Mental Health and Mental Retardation. All possible media should be used, including newspapers, television, professional journals, conferences and any other means available. It is recommended that the Department establish means to counsel parents of children at risk for mental retardation, including genetic counsel. This will require the identification and assistance of persons with expert knowledge.

    Particular importance is attached to expanding and improving public school family life curricula to include:

    a. Early childhood development
    b. Adequate nutrition
    c. Preparation for parenthood
    d. Family life education
    e. Principles of genetics

2. A coordinator for preventive programs is needed. This person should be responsible to the Governor.

    a. Responsibilities include publicity plus evaluation of existing programs and development of new programs.
    b. Maximize coordination and cooperation both at local and state levels, especially between Mental Health and Mental Retardation and Departments of Education and Health.
    c. The coordinator is intended to be a person whose primary mission is to reduce the incidence of mental retardation by obtaining increased support for existing state agencies, facilitating their ability to meet needs and able to identify and create interest in all appropriate parties. He or she, especially, must be able to work effectively with professionals already engaged in the prevention of mental retardation.

3. Mental retardation is remarkably increased among the poor and poorly educated. Particular attention should be directed to citizens in these groups.

Optimal care decreases brain damage in sick newborns and children born of complicated pregnancies. Regional centers should be established for the management of mothers whose pregnancies are at high-risk for the production of damaged offspring. Both ambulatory and inpatient centers should be considered and careful attention paid to obtaining the informed cooperation of the patient's personal physician.

Further improvement in programs for prenatal and early postnatal nutrition such as the current Women's, Infants and Children's Nutritional Program are effective means for reducing mental retardation. Participation in this program should be expanded.

6. It is possible to screen appropriate persons for cytogenetic causes of mental retardation. The state should expand current programs and establish new ones.

7. It is possible to screen appropriate persons for biochenical causes of mental retardation. The state should expand current programs and establish new ones.

8. Appropriate immunization programs must be expanded to prevent diseases which cause mental retardation.

9. Appropriately trained specialists are in short supply. The state should give priority to funding and developing resources at its three medical schools to train physicians and other health personnel in genetic counseling, the management of risk pregnancies, public health and the management of the neonate-at-risk.

10. Steps should be taken to improve the reporting of developmental problems and perinatal events, with particular attention to improving the quality of obstetric and neonatal care. A uniform record should be used throughout the state to facilitate the collection of needed and useful data.

11. A telephone hotline should be established for resources dealing with the prevention and management of mental retardation. Available services should be made known and there should be documentation of the need to expand these services and establish and fund new ones.

12. A check-list of activities which are a proper responsibility of the state has been drawn up by the Association of Retarded Citizens and is included in the Appendix B, page 33.

Specific Recommendations

Rubella

Allert the public to the relationship between the disease and its damaging effect on the fetus.

Inform the community that this damage to unborn infants can be prevented.

Support and promote widespread and continuous immunization programs, particularly for children, who constitute the major source of spreading the disease.

Check the availability and use of the HI blood test for women considering marriage or planning a pregnancy. Assure that the test is available to all who need it, by a laboratory specifically approved for this type of testing.

Find out from existing maternity care resources the availability and use being made of the HI blood test to confirm or rule out a rebella infection in women who are pregnant and who suspect they have been exposed.

Lend public support to state health department efforts to develop and carry out immunization and blood-testing programs.

Chromosome Abnormalities

Include information about chromosome abnormalities in public education programs.

Assure that high school curricula for biology and health courses include information about chromosome abnormalities and the process for detecting them.

Check with local hospitals and county medical societies regarding the availability of amniocentesis procedures for those families who desire it.

Explore the costs of amniocentesis, genetic analysis and family counseling in your community. If costs are high, explore other payment methods to assure that the families at risk are not deprived of these procedures because of their financial need.

Metabolic Disorders

Develop interest in hospitals, physicians and state health departments in testing for a wide range of biochemical disorders.

Inform the general public and expectant mothers of the importance of testing and subsequent dietary treatment. Contacts should include obstetricians, pediatricians, medical societies, public health nurses and community clinics.

Explore the possibility of the state's participation in a regional laboratory to reduce costs while, at the same time, screening for a greater number of disorders and diseases.

Prenatal Care

Urge community action to assure that the local school system curricula include information on good nutrition, with particular emphasis on pregnant mothers.

Plan and implement programs on the importance of prenatal care. A vital element of this project is assuring that such data reaches women of child-bearing age.

Assess the availability of public and private prenatal care services in the local community and support the establishment of maternal health clinics where needed.

Support legislation and appropriations for maternal care programs.

Establish liaison with minority and "high risk" groups and develop cooperative methods to promote full utilization of available prenatal care facilities.

Prematurity

Review curriculum guides of the local school system for inclusion of information on good nutrition with particular emphasis on pregnant mothers.

Participate in volunteer programs to bring information and assistance in planning and preparing nutritious foods to low income groups.

Plan and implement programs that will disseminate information on the importance of prenatal care to target groups.

Assess the availability of public and private prenatal care services in the local community and support the establishment of maternal and infant health clinics where needed.

Support legislation and appropriations for maternal and infant care programs.

Acquaint the public, and young people in particular, with the health hazards of tobacco and other drugs as toxins, and especially their contribution to prematurity.

Support the establishment of specialized premature nurseries and transportation systems for bringing infants to such centers. Premature nurseries should also be investigating the necessary stimulation to help the infant develop properly while confined to the nursery.

Establish liaison with minority and high risk groups to develop cooperative methods to promote utilization of available prenatal care facilities by high risk populations.

Malnutrition

Urge public recognition of high protein vegetable products as substitutes for expensive and often low protein products.

Enlist the mass media in stressing the importance of increased nutrient requirements of women during pregnancy and infants during the first year of life.

Stress the advantages of breast feeding.

Develop educational programs for both lay audiences and professional persons.

Urge the establishment of special high school programs designed to inform adolescent girls of the importance of good nutrition during pregnancy. Increasing numbers of pregnancies among adolescent girls and the decreasing age at which girls become pregnant demand this special consideration. Of all age groups, adolescent girls are most apt to have inadequate diets.

RH Blood Disease

Promote public understanding of the need for Rh Testing and the fact that Rh blood disease is completely preventable through early treatment.

Work with clinics, social agencies and others concerned with poverty area residents, to assure that Rh preventive measures are understood and utilized.

Check with local hospitals and obstetricians to assure that Rh factor testing is done prenatally and that the immunoglobulin is available to every woman who needs it.

Assure that Rh-negative mothers already sensitized to Rh-positive babies have careful prenatal care and monitoring for Rh problems. Immunoglobulin treatment is of no benefit to mothers already sensitized to make the Rh antibodies.

Respiratory Distress Syndrome

Urge the establishment of perinatal programs that will allow monitoring the high risk mothers during pregnancy and labor and give special attention to infants at birth and in the first critical days thereafter.

Assure that high quality intensive care is made available to all infants. Support community efforts to establish regional intensive care units.

Establish effective means of transporting premature infants born in smaller hospitals to effective regional centers.

Neonatal Narcotic Addiction

Support community efforts to gain early prenatal care for addicted mothers.

Provide public information on the importance of adequate nutrition and the control of narcotic intake in reducing medical and obstetrical complications.

Emphasize the need for specialized medical care and follow-up of the infant.

Venereal Disease

Promote public awareness and education of the cause, symptoms and cure of venereal disease. Prevention and curative treatment is possible, but the stigma and guilt associated with gonorrhea or syphilis often causes them to go undiagnosed and untreated.

Promote awareness of the need for women to obtain blood tests early in their pregnancy to detect and prevent transmission of syphilis. Regular examinations during pregnancy to detect infection in the cervix and vaginal area are equally important for the cure of gonorrhea.

Support community efforts to urge hospitals to treat newborns with appropriate eyedrops to prevent gonorrheal eye infection.

Promote specific health education programs through schools, church groups, service organizations and other youth groups. Public education, awareness and concern are essential as apathy and ignorance are the major obstacles to control and prevention. Such programs carried on through schools or through the mass media have repeatedly shown a reduction in the disease.

Lead Poisoning

Checking homes in high incidence neighborhoods for sources of hazardous lead exposure, such as chipping paint, plaster, etc. The State Health Department can identify community contacts for testing.

Alering high incidence neighborhoods to the dangers of lead poisoning through public information and educative measures.

Checking labels of toys and other items with which children are likely to come in contact for lead-free content.

Checking of retail outlets for lead paint that might be used on houses, furniture, play equipment or any object with which children might come in contact.

Checking earthenware (particularly those items imported and those made by hobbyists) and pewter ware used for culinary purposes. The lead content of suspected materials can be analyzed by the health department.

Developing tecnhiques to bring hazardous sources of lead exposure under control.

Checking existing laws and regulations to assure that they are being enforced effectively.

Encouraging the development of relatively simple and inexpensive techniques whereby the lead paint hazards of old housing can be brought under control.

Participating in and supporting public education efforts on the problem of childhood lead poisoning.

Assuring that screening programs not only identify children suffering from acute lead poisoning but also those in the early stages of lead absorption.

Participating in and supporting the development of treatment programs with adequate follow-up services.

Developing a cooperative effort with health professions, community workers, housing authorities and others concerned with the problem to ensure that undue exposure to lead is terminated promptly once children are found to be exposed. Children should not be returned to the same hazardous environments until the source of lead is removed or covered over with wallboards or some other suitable method.

Child Neglect and Abuse

Every state now has laws governing reporting of physical abuse -- but laws alone cannot prevent abuse. Prevention, early intervention and parent help is urgently needed. While legislatures have been quick to pass laws on this subject, actual funding programs are harder to come by. Community groups should urge the development of financial support to fight child abuse.

Communities should be urged to establish well-staffed offices in the responsible public agency which can respond immediately to reports of neglect or battering.

Appropriate support services for the child and the family should be provided promptly.

Trained hospital teams are needed in addition to greater medical awareness.

Resources should be provided for care of the child out of the home if such a step is indicated. Appropriate support in the home may avoid this additional crisis.

Comprehensive multidisciplinary community programs are needed which focus on a combined community-hospital child abuse program. Centralization and coordination of skills and services are badly needed. Physicians and hospitals are frequently reluctant to get involved with these families because of lack of services to extend needed help to the family beyond crisis care in the hospital.

Other new community resources might include telephone "Hot Lines", personal guidance and supportive services, day care services, parent-group programs, parent aid and homemaking services. Needed disciplines include social, legal, medical, psychological, nursing and religious. Lay therapists, aides and foster grandparents have been very effectively used in a few communities. One centralized program must exist to be responsible for recruitment, training placement and follow-up.

There are a number of agencies and professionals to aid in securing support in detection and elimination of child abuse:

Local Health and Welfare Departments
County Medical Associations
Child Welfare Leagues or other interagency service organizations
Attorneys and Judges
Community and Children's Hospitals

Promote community meetings to discuss the services and needs for prevention and control. Involve city councils and state legislatures to attain necessary money and new laws.

Urge concerned youth organizations and other groups to participate directly in the provision of services such as child care. Youth groups can encourage classes on child care and child development in their own schools so that young people may learn child-rearing skills. Some high school classes are already allowing students to train in nursery and preschool child care centers.

Poison Control

Urge community action toward effective poison control committees and workable programs.

Assure that medicines are being dispensed in child-resistant containers and kept well above the reach of young children.

Promote first aid programs to teach parents and youngsters the proper techniques for emergency treatment in cases of poisoning.

Make sure poison prevention is a part of the local public school curriculum

Promote Poison Prevention Week as an annual community event. Information for such activities is available through the National Clearing House for Poison Control Centers.

Identify local resources that could be helpful in poison prevention programs:

Poison Control Centers
Health Departments
Communication Media
Public Schools
Physicians
Public Health Nurses
Social Workers in Public Agencies
Red Cross or Civil Defense First Aid Programs

Maternal Diabetes

Encourage local groups to consult health departments and medical societies regarding the availability of proper resources. These should include facilities for prenatal care and family planning help.

Community action should include development of programs to adequately fund vital health resources and provide special equipment, staff and transportation of new babies to treatment centers.

Promote programs for regular community screening for diabetes. Health education courses for high school students should stress the importance of recognizing and managing health needs of the pregnant woman.

Develop public education and awareness programs concerning the need for special care during pregnancy.

Maternal Age

Support effective family life, health and sex education programs for adolescents or pre-adolescents.

Promote inclusion of information on "effects of maternal age" in school health education curricula.

Develop community public information programs on hazards of reproduction at age extremes.

Support family planning information and services.

Promote the availability of anmiocentesis services to the women who do become pregnant in their 40's.

Early Detection and Intervention

Support the establishment of sophisticated screening programs to identify infants "at risk" who may need the special efforts of a professional team.

Promote development of infant programs designed to provide the special skills needed by handicapped or atypical infants. An essential component of any infant program is parent involvement. Parents need help in fostering appropriate and beneficial relationships with their children, and the infant is frequently best served by providing counseling and teaching assistance to the family.

Support community surveys of hospitals, obstetricians and pediatricians for identification of high risk pregnancies and infants.

Health Education Programs

Promote the inclusion of health education programs in school curricula.

Enlist the aid of local organizations such a health departments, medical societies, nursing associations, family planning clinics and nutrition councils.

Develop discussion sessions with school administrators -- express the community's concern with the importance of programs for preventing mental retardation.

Enlist the support of local nursing associations, health departments and medical societies in reviewing and expanding educative programs.

Public Awareness

Library displays
Utilize existing health agencies
Utilize elementary school and high school health classes
Utilize parent groups in the school (PTA)
Utilize high school clubs for presentations
(e.g. Future Homemakers of America, Future Nurses of America, Future Teachers of America, Student Council)
Establish a booth at career motivation days and distribute material
Use mass media -- radio, newspaper and TV -- for spot announcements promoting your association's prevention campaign

DIRECT SERVICES TO PREVENT MENTAL RETARDATION

Overview

Mothers, infants and children comprise two-thirds of the population, and are a population group most vulnerable to conditions which cause or predispose mental retardation. Preventable causes of mental retardation which may affect mothers and children result in a great expense to society in professional resources, loss of tax revenue from non-productive citizens, wasted human potential, and financial outlay far greater than the cost of preventive services.

Because of their vulnerability, mothers, infants and children require special services to meet their health* needs. Every mother and child should have access to preventive health services of high quality to include:

1. Family planning.
2. Prenatal care including amniocentesis for mothers at risk of bearing infants with prenatally detectable conditions causing mental retardation and other defects.
3. Regionalized intensive care of the high-risk pregnancy and delivery.
4. Regionalized intensive care of the high-risk newborn.
5. Primary pediatric care including neonatal screening for conditions causing mental retardation, immunizations, and periodic comprehensive screening for potentially handicapping conditions including developmental delay.
6. Parental anticipatory guidance in child development and infant stimulation.
7. Nutritional education with nutrition supplementation for the indigent.
8. Multidisciplinary in-depth diagnostic evaluation and treatment including genetic study and consultation of suspected handicapping conditions including suspected mental retardation.

The State Department of Health largely through Maternal and Child Health and Family Planning Bureaus and local health departments provides all of the above services statewide except for regionalized maternity and newborn care, now in development. These preventive services are limited by volume of service delivered.

* WHO definition of health: Mental, physical, and social well being. Studies and practice in child development, yield increasing evidence that bio/socio/psychological factors are interrelated in their effect on child development, separated with increasing difficulty.

I. Prevention and Treatment of the High-Risk Pregnancy and the High-Risk Newborn

Prenatal care with special care of high-risk conditions prevents low birth weight and mental retardation. Lack of prenatal care is associated with greatly increased risk of low birth weight and other complications of pregnancy and the newborn which lead to neurological abnormalities of the infant. The poor have a four to five times greater chance of prematurity and low birth weight, and other complications of pregnancy.

Thirty percent of all pregnancies among the poor, annually 7933 in Virginia, are high-risk. Sixty percent of all high-risk infants are born of high-risk pregnancies. Seven and one-half percent of the State's pregnancies are low birth weight among whom 50% will have significant handicaps, and 70% of low birth weight pregnancies occur among the poor. The poor, low birth weight infants are an important at-risk group for mental retardation.

While 1% of normal birth weight infants have moderate to severe mental and/or neurological and/or physical handicaps, the rate is markedly increased for infants under 5-1/2 pounds. In Virginia, 5,480 infants had a birth weight less than 5-1/2 pounds in 1973, a rate of 7-1/2%. These are high-risk infants by definition. Fifty percent of these low birth weight infants and up to 70% of other high-risk infants treated in regular nurseries will have significant residual disability. Intensive care nurseries reduces the rate of significant disability among the survivors to 10%.

Current situation: Cost of care of low birth weight in regular nursery plus cost of care of handicapped survivors:

$125/day (State average)	x	22 days (State average)	x	5480 (Infants)	$15,070,000
	+				+
2740 (handicapped survisors)	x	$65,392*			179,173,280
					$194,243,280 (total)

Proposed: Cost of care in Intensive Care Nursery for the estimated 3217 low birth weight and other high-risk infants who would require it plus cost of care for handicapped survivors:

$300/day (national average)	x	20 days	x	3217	$19,302,000
	+				+
322 (handicapped survivors)	x	$65,392*			$21,056,224
					$40,358,224 (total)

*A conservative estimate of average cost per patient. From a national study of health and economic costs of rubella sequelae, 1966. Patients' disabilities were mild to severe. Medical care, institutionalization, special education or regular education, were included. 1966 figures are used, discounted 4%, with no allowance for inflation. Loss earnings factor is not included. HEW-PHS publication 2211207375, March, 1975.

Currently, intensive care of the newborn at the highest level of care is provided at the hospital nurseries associated with the three medical schools in the State. Five other hospitals in the state provide an intermediate level of care. Only a fraction of those infants needing this care receive it, for a variety of reasons including transportation difficulties and local pride.

Present Status	Proposed
Mothers: to prevent low birth weight and other high-risk conditions of pregnancy and infants:	
1) Family planning program of State/ local health departments now reaches 50% of eligible population.	1) That State Health Department request additional positions for Public Health Nurses and aides to extend activities be supported.
2) Prenatal care of medically indigent can be documented for only 1/2 of eligible population.	2) That State Health Department request for additional positions for Public Health Nurses and aides to extend activities be supported.
3) Physicians are withdrawing from service in prenatal clinics of State/ local health department. Explanation: Health Department pays for care in hospital for complicated cases, has no funds to pay for hospitalization of normal deliveries, and none to pay physician for delivery of normal or complicated cases. Only 1/4 of medically indigent population is eligible for Medicaid.	3) That funds be made available for hospital delivery and physician payment for all uninsured and medically indigent mothers. That State Health Department utilize nurse practitioners and nurse mid-wives in prenatal care and normal deliveries, and that funds be made available to support such positions.
4) There is no plan for statewide identification and referral to a resource center for treatment of high-risk pregnancies, and meager resources for special care of high-risk pregnancies.	4) That State Health Department with State OB-GYN Society immediately prepare a plan for regionalized care of pregnant and perinatal patient, and implementation beginning in January, 1977. Plan should be coordinated with Plan for Regionalized Care of Newborn (see below)
5) Nutrition - see below	

Present Status	Proposed
Infants: to provide early detection and intensive care of high-risk infants:	
1) State Health Department - MCH is required by Federal mandate to develop a plan for statewide Regionalized Care of the Newborn. Planning is underway with the Fetus and Newborn Committee of the Virginia Chapter, American Academy of Pediatrics.	1) That the State Health Department with Fetus and Newborn Committee complete a plan for regionalized care of the newborn and implement immediately. That requests by the three medical schools for funds to improve maternity nursery units be supported.
2) State Health Department - MCH has the responsibility to provide hospital maternity/nursery consultation to assure that every hospital maternity/nursery unit complies with State regulations for care of mother and newborn*, to provide or support professional education, and to see that there are proper procedures for identification, referral and follow-up for high-risk infants. This important work is done only in severe emergencies (such as a virulent staphylococcal epidemic in a hospital nursery) because of insufficient staff.	2) That the State Health Department - MCH provide annual monitoring and consultation visits to maternity/nursery units of all hospitals in Virginia, as recommended by the Fetus and Newborn Committee of the Virginia Chapter, American Academy of Pediatrics. Funds to support this activity should be provided. That uniform perinatal clinical record forms be utilized statewide to make possible the obtaining of information regarding health and nutritional status of mothers and infants and to provide a tool for quality control.

* This is in addition to regular inspection by Bureau of Medical and Nursing Facilities Services.

II. Comprehensive Screening, Diagnosis, and Treatment for Infants and Young Children

Facts: Studies by HEW indicate 60% of the chronically disabled between 18 and 65 years of age who receive welfare subsistence and Medicaid are disabled by conditions preventable in childhood. Cost to Virginia taxpayers as a result of lack of child health services to 19,050 disabled Virginians (1970 figures) whose conditions were preventable:

19,050	x	$1800/year Medicaid (58% Federal, 42% State)	34,290,000
19,050	x	$1884/year support (average SSI - Federal and State)	= 35,090,200
			69,380,200

Total cost does not include loss of earnings if client had been a productive citizen. Only 1/4 of the State's medically indigent are eligible for Medicaid. Health departments provide screening examinations for Madicaid recipients. One-half the State's newborns of the medically indigent are seen in health department clinics, and a much smaller share of preschoolers.

Immunizations: Federal funds to purchase expensive viral immunizing materials are no longer available, threatening future immunization levels of preschool children.

Cost to State of immunizing material for 50,000 medically indigent 1 and 2 year olds: $121,000 as compared with cost to State of caring for severely brain-damaged children that will result from 25-50 cases of measles encephalitis in that population if left unimmunized: $6,250,000. (Cost of loss of earnings not included; inflation factor not added.) Cost to State in caring for 84 cases of handicapped children as a result of the next wave of rubella if child-reservoir is left unimmunized: $5,494,928 (84 x $65,932). Total cost $11,744,928 as compared with $121,000 for vaccine.

Postnatal Biochemical Screening: The experience of the phenylketonuria (PKU) program in Virginia over the past eight years supports the concept of screening neonates for treatable metabolic disorders before they suffer mental retardation therefrom.[1] Approximately four children with PKU have been detected each year, and they have subsequently developed normally while maintained on an appropriate phenylalanine restrictive diet for the first six years of their life. Had these four infants not been diagnosed early and treated, such severe mental retardation would have resulted that they would have had to receive institutional care for the majority of their lifetime. The cost of such care would be approximately one million dollars ($5,000/year x 50 years x 4 patients), whereas the cost for screening and treating these children is approximately $38,000/year (or approximately $0.50 per neonate screened). An unexpected additional benefit of this program has been the realization that asignificant number of young infants

(approximately 9/year) were suffering from a related disorder (severe transient neonatal tyrosinemia) which also caused a positive screening test. This condition, previously thought to be innocuous, has recently been shown by Virginia State Health Department physicians to be deleterious to the developing nervous system.[2] With this realization, and with the understanding that its cause is an excessively high protein formula, public health and nutrition education programs were instituted which effected a reduction of its incidence to 1-2/year over the past two years.

Periodic Screening: Pediatric periodic screening, early identification of disorders of health and development, anticipatory parental guidance in child health and development, and primary care and intervention with appropriate referrals are integral parts of State Health Department standards for child health services of local health departments. Cost benefit analysis is yet incomplete. Overwhelming evidence in scientific literature and in Virginia institutions for the retarded and delinquent indicate that without the preventive services described above, Virginia's taxpayers will pay a heavier price for rehabilitative, and custodial services than they might have paid for adequate preventive services in well child and primary care for children of the medically indigent.

Implementation of 22-10.4 by which preschool children with handicapping or potentially handicapping conditions must be identified and provided special education is a major preventative against functional mental retardation. The Interagency Task Force assigned local health departments statewide to be the points of entry for children suspected of having handicapping conditions. Periodic screening of health and development from birth is essential to detect possible handicapping conditions and to make appropriate referral for further evaluation. Local health departments can now do only a fraction of the screening needed, and are not able to perform preschool exams for all medically indigent children as they are mandated to do.

Present Status and Proposals

The success of the Virginia PKU program (which tests 97% of the births each year) dictates consideration of screening for more than 50 additional disorders which are known to cause mental retardation. The feasibility of such testing relates mainly to:

1. Frequency of the disorder
2. Ease, cost and reliability of testing
3. Prospects for treatment

The ease and cost of testing for additional disorders would be considerably reduced if the laboratory used the same blood discs already being submitted for PKU screening and if multiple testing could be at least partially automated.

Most of the screening tests that have been developed for approximately twelve additional disorders do utilize this specimen, and an automated machine is now available which simultaneously punches out four blood discs and places them on four spearate testing trays.[3] Four states (California, New York, Massachusetts and Oregon) and many foreign countries have for several years screened for 4-8 disorders, and their expenses with such programs have been carefully reviewed by the committee.[4]

Based on the above factors, the committee strongly recommends that the following additional three blood tests be performed on the same specimen available from the already existent PKU screening program.

1. Radioimmunoassay of thyroxine to detect Hypothyroidism

   a. The frequency of the disorder has recently been shown to be 1:7,000 births.[5]
   b. The test can be run by one technician utilizing an automatically punched disc. It is very reliable and the cost is approximately $0.50/test. Because neonatal hypothyroidism usually is not diagnosed until a significant degree of irreversible mental retardation has occurred (with a cost to the state of a minimun of $65,000 for special education and care per child), it is clear that it is worthwhile to spend $3,500 ($0.50 x 7,000 tests) to early detect each case.
   c. At the present time, it is believed that the institution of thyroid replacement therapy to the hypothyroid neonate will avert mental retardation. The therapy is simple, inexpensive, and has essentially no adverse side effects.

2. Beutler enzyme test for GALACTOSEMIA[6]

   a. The frequency of the disorder is approximately 1:35,000.[7]
   b. The test is highly specific and reliable, having been utilized for over five years by some state screening programs; in the summer of 1974 this procedure was successfully developed at MCV for use by the State Division of Consolidated Laboratory Services. It can be performed from an automatically punched disc at a total cost of approximately $0.10 per specimen or $3,500 ($0.10 x 35,000) per detected case.
   c. Undetected galactosemia causes either death in the first two weeks, or significant psychomotor retardation due to an accumulated intermediate of galactose metabolism, galactose-1-phosphate. Early treatment of the disorder prevents these complications and entails merely the strict dietary restriction of milk and milk products (the major galactose containing foods).

3. Bacterial inhibition assay for HISTIDINEMIA

   a. The frequency of the disorder is approximately 1:18,000.[8]
   b. The test is highly specific and reliable and has been utilized by several states and foreign countries for many years. It is run in exactly the same way as is the PKU test, and, as one of a battery of four tests to be automatically punched from the submitted blood disc, would add a cost of no more than $0.10 per patient.
   c. It is not clear which children with histidinemia will suffer psychomotor retardation, usually of a mild degree; the most extensive data suggests that 40% are adversely affected. With this high an incidence, until a prediction of outcome can be developed, it appears warranted to attempt to lower serum histidine levels with a histidine restrictive diet.

In addition to the above blood tests, the committee recommends that urine specimens from all two to three week old neonates be screened with a battery of simple chromatographic and other qualitative tests to enable the detection of a minimum of an additional eighteen metabolic disorders, at least eight of which are frequently causative of mental retardation (see attached listing with incidence figures).[9] They are not recommended separately for screening as with the previously four disorders for one or more of the following reasons: a) their incidence is too low, b) there is no adequate treatment, or c) a screening test for the disorder is either not available or not reliably positive in the early neonatal period. Testing the urine at this time also serves to detect any cases of PKU, galactosemia, or histidinemia missed on the first screening. As it operates in Massachusetts, the mother would be given written instructions (at the time of her infant's discharge) regarding the method of impregnating filter paper with urine and mailing it to the State Division of Consolidated Laboratory Services. Operating as a new and separate service this urine testing procedure might be too expensive for the number of treatable disorders detected, but when done by a team of technicians already involved in metabolic screening, the cost would be minimal (approximately $0.20/test, including a prepaid mailer).

Both the Massachusetts and Oregon State Health Departments have presented cost/effectiveness studies of a program such as is proposed herein.[10] The former (with a yearly birth rate of approximately 60,000) estimates a yearly savings of $364,000 and the latter (approximate yearly birth rate of 20,000) a yearly savings of $600,000, excluding any consideration of lost earnings or taxes. Additionally, these savings were calculated before the recent advent of screening for hypothyroidism, the most frequent disorder recommended for testing.

The above proposed screening programs would not be feasible were there not appropriate followup testing, treatment and genetic counseling available at the Virginia medical schools. Such backup support has been essential to the successful operation of the PKU program and would be even more important with the suggested broadened battery of disorders screened.

In implementing the above proposals the State Division of Consolidated Laboratory Services would have to undergo a considerable amount of restructuring in order to: a) centralize its screening activities (presently dispersed in three laboratories across the state), b) develop technicians with expertise in the field, and c) assure adequate supervision and communication with its metabolic consultants. The minimal number of personnel required to operate such a program would be four technicians ranging from a senior chemist to a laboratory assistant, two clerks, and a metabolicist-consultant.

Virginia state law (Act 32-112.20 through 32-112.23) has already mandated the screening of genetic disorders. The methodology needed for such screening has been developed over the past five to ten years, and Virginia has the necessary expertise to implement these tests. What is presently needed is appropriate funding to support the expanding of State Division of Consolidated Laboratory Services capabilities in this area. Only then will it be possible to further reduce the incidence of mental retardation caused by inborn errors of metabolism.

Additional Disorders Detected by
Urine Chromatography and Other Qualitative Tests

Disorder	Incidence
Iminoglycinuria	1:10,000
Cystinuria	1:16,000
Hartnup disease	1:18,000
*Argininosuccinicacidemia	1:70,000
Cystathioninemia	1:110,000
*Homocystinuria	1:150,000
*Organicacidemias (methylmalonic, proprionic, and isovaleric acids)	1:150,000
*Hyperglycinemia	1:170,000
*Maple syrup urine disease	1:170,000
Hyperlysinemia	1:300,000
*Tyrosinosis	1:300,000
Hyperornithinemia	1:300,000
*Citrullinemia	1:300,000
Fanconi's syndrome	1:300,000
Hyperprolinemia	1:300,000
Hereditary fructose intolerance	?
Galactokinase deficiency	?

*Disorders frequently causative of mental retardation

Present Status	Proposed
1) Neonatal Screening is done now for PKU, as mandated by State law. Consolidated Laboratory Services are not sufficient to screen for other treatable conditions which untreated cause mental retardation.	1) That the request of the Consolidated Laboratory to extend screening services for newborns be supported.
A nutritionist is an essential member of the treatment team and can only be efficient and skillful if working exclusively in the field.	That the State Health Department request for a full time nutritionist for PKU and other Inborn Errors of Metabolism be supported.
2) Health Department may not receive funds to purchase immunization materials no longer provided by Federal government.	2) That the State Health Department be provided funds to purchase measles/mumps/Rubella vaccine (50,000 doses = $121,000)
3) Half the newborns of medically indigent citizens receive services which prevent mental retardation in local health department clinics, and a much smaller number of preschoolers.	3) That the State Health Department request for additional staff to increase clinic services to medically indigent infants and children be supported.
Mandated early detection of handicapping conditions and preschool exams cannot be done in volume needed.	

III. Nutrition Education and Nutrition Supplementation for Indigent Mothers and Children.

National studies and one nutrition survey in Virginia indicate that:

malnutrition occurs in all economic groups
money alone will not correct malnutrition
nutrition education is needed by all income groups
some form of economic assistance is require to improve nutritional status of the poor

Mothers, infants and young children are vulnerable to poor nutrition which results in irreparable damage to the developing brain.

The optimum weight gain during pregnancy is between 25 and 35 pounds with regard to neurological abnormalities of the infant including mental retardation. In spite of professional education efforts by the State's medical schools, and the State Health Department in the past 5 years, there is much evidence that customary practice among practicing physicians treating pregnant women is to advise limitation of weight gain to less than 20 pounds. A complexity of adverse bio/socio/economic factors including nutrition are associated with higher incidence of neurological abnormalities. Women in lower income groups have the poorest outcome of pregnancy, epidemiologically.

Cost benefit analysis is not yet feasible, but a 1968 Budget Bureau report estimated that elimination of hunger and malnutrition in the U. S. would bring a three-fold return on the investment in the form of increased taxes from more productive citizens. One small study conducted in Virginia by Dr. Peter Mamunes in cooperation with the State Health Department yields statistically and clinically significant evidence of the need for nutrition education to prevent mental retardation: a series of infants, mostly asymptomatic, who were fed inappropriate dilution of infant formula were found to have lower average IQ and greater incidence of specific learning disabilities at ages 4 and 6 years as compared with matched controls.

Present Status	Proposed
1) Nutrition Education: State Health Department Nutrition Section consists of 4 full time, 4 part time, and 3 special project nutritionists to serve the State. In cooperation with Bureaus of Maternal and Child Health, they educate health department and private practice health professionals, in addition to clinical duties. By national standards, Virginia's population requires 93 professional nutritionists.	1) That the State Health Department Nutrition Section be expanded to 93.

Present Status	Proposed
2) Information about nutrition and health status of infants and children is not systematically captured, statewide, although data for each health department patient is recorded locally.	2) That systematic nutrition surveillance become an integral part of Maternal and Child Health Services statewide, including Medicaid screening, and school children (as a lower priority as compared with infants and preschool aged).
3) Nutrition Supplementation: "WIC" - Supplemental Food Program for Women, Infants, and Children, as a federal program by which a health clinic prescribes specific nutritious foods by voucher redeemed at the local grocery store. One locality in Virginia has such a program conducted by the local health department. Current deliberations of Congress will decide the continuation of the program.	3) That a "WIC" program be established statewide, should this federal program be extended beyond 1975, with nutrition education as an integral component of the program.

IV. Multidisciplinary In-depth Diagnostic Evaluation and Treatment Including Genetic Study and Consultation of Suspected Handicapping Conditions.

Early identification of suspected developmental problems with appropriate intervention is frequently an effective means for the prevention of a permanent condition of mental retardation. The State Health Department conducts 12 regional Child Development Clinics which provide multidisciplinary, interagency (with State Department of Education) diagnostic and treatment services. These Clinics play a key role in the Interagency State Plan for Identification and Diagnosis of Handicapped Children for Implementation of 22-10. 4 (see attached).

In-depth diagnosis of handicapped children is necessary in most cases before appropriate genetic counseling of parents and siblings can be done.

Regional Child Development Clinics serve as resource centers for information on child development, as well as provide for diagnostic evaluations and selected developmental comprehensive treatment services for children with developmental difficulties. The treatment program devised is often multi-faceted involving parent, family doctor, schools, and many other community agencies. Although waiting lists for most of these clinics is long, a high priority emphasis is placed upon the preschool and early school age child.

Present Status	Proposed
1) The 12 regional clinics are not fully staffed, but many must function with some part time members of the team. Efficiency of operation is reduced, and quality of team effort suffers as a result.	1) That 12 additional positions be authorized to complete the staffs of the Regional Child Development Clinics, giving each clinic at least one representative of each of the core disciplinary staff.
2) State Departments of Education and Health are planning closely for coordination of service. Because of strong emphasis on local antonomy, the State Department of Mental Health and Mental Retardation is able to coordinate to a limited extent only in the State Plan.	2) That there be efforts for additional coordination between the State Department of Mental Health and Mental Retardation and the State Department of Health and Education for the implementation of 22-10. 4.

V. Prenatal Diagnosis

Chromosomal Aberrations: Many chromosomal disorders (including the most frequent one, mongolism) most of which irrevocably cause severe mental retardation, occur in increasing frequency with advancing maternal age. With the advent of safe, reliable amniocentesis and culturing techniques it has been shown to be economically and medically feasible to monitor the pregnancies of all women age 38 and older.[11,12] Termination of the pregnancy would be offered where the analysis of the fetal cells detected a chromosome imbalance (usually mongolism) known to cause moderate or severe mental retardation. Chromosome disorders occur in approximately one in each 800 live births.

As an indication of the savings of the state for the detection of mongolism alone, the following accounting is offered:

a. Yearly incidence of births to women age 38 or greater = 2% of 71,665 = 1,443.

b. Frequency of mongolism in infants born to women age 38 or greater - 1:100.

c. Number of mongoloid infants born to women age 38 or greater (1443/100) = 14.

d. Cost of institutionalization of 1/2 of 14 cases surviving to age 15 and placed in custodial care from that age to age 55 - 40 (years) x $6,100 (cost/patient/year) x 7 (number of patients) - 1.7 million dollars.

e. Cost of screening the 1,443 susceptible pregnancies = $200 (cost/test) x 1,443 = $288,600.

f. Savings to State = $1,700,000-$288,000 = $1,400,000.

Metabolic Disorders: A fetus can be determined to be a risk (either 1:4 or 1:2 risk) for a metabolic disorder causing mental retardation by one of two ways:

a. Occurrence of the disorder in a prior offspring.

b. Identification of both parents as carriers through screening in at-risk populations (eg., Tay-Sachs screening of Ashkenazi Jews).

In many of these metabolic disorders the enzyme status of the fetus can be determined by culturing cells obtained by amniocentesis; if no enzyme activity exists the prediction of mental retardation can be made and the parents offered the option of terminating that pregnancy. Approximately ten such studies are indicated each year in Virginia and the number will increase as more and more metabolic disorders are described and further methods of enzyme measurement in fetal cells are established. Laboratories qualified to provide this necessary service presently exist at the University of Virginia and the Medical College of Virginia, but financial support is urgently needed for their further development.

Present Status and Proposal

The State Health Department has recently undertaken a statewide program of free amniocentesis for women over age 40 and those with other conditions indicating an increased risk of bearing a chromosomally anomolous child. However, the program is woefully underfunded, and only a small fraction of the eligible women are being tested. With proper education of the lay and medical communities (as discussed elsewhere in this report), and with lowering of the age of testing to any women age 38 or older (as recommended by authorities in the field), much more financial support will be needed.

As with the postnatal screening of metabolic disorders, a program of prenatal screening of chromosomal and metabolic disorders requires the more extensive development of centers (at the three Virginia medical schools) for the medical, therapeutic (eg. dietary) and genetic counseling support of these patients and their families.

EDUCATION AND PUBLICITY

Educational programs for the general public and professional health care teams are considered by this committee the cornerstone of primary, secondary and tertiary prevention of medical causes of mental retardation.

We propose introduction into the curricula in state institutions educating health and educational professionals the full knowledge of material on the subject. Without such a resource these professionals are seriously handicapped in their work and service to the public. Review of curricula, texts and examinations is recommended on an annual basis so as to perpetuate awareness and to add new concepts.

Routine circulation among health and educational specialists of journals on mental retardation is obligatory as well as statewide continuing education seminars for interdisciplinary groups. Acknowledgement for participation in continuing education in the field should be recorded by certificate, licensure stamp or examination. The State of Virginia may work through professional organizations to promote the collaboration and implementation of such programs.

Public and private school systems currently present health and behavioral science courses which must include material on mental retardation. The foundations for responsible and competent parenthood are laid down in childhood; and without knowledge available, the people become helpless to cope with the issue in their personal lives. Reproductive responsibility is an issue which can and must be inculcated prior to the development of reproductive potential.

Fragmented service and information to unwed mothers and families giving birth to infants with genetic, congenital, infectious or premature conditions should be obliterated. It is suggested that a multi-disciplainary team be formed by the state public health system to respond to all families at the birth of a high risk infant for mental retardation, regardless of social or financial status. This team is expected to present diagnostic interpretation, treatment potential, and prognostic information. Service resources and financial resources and expectations should be made available by the team. Annual consultation for support and reevaluation should be provided. Such a multi-disciplainary team can serve as a public information resource as well as a resource to the state human services staff for needed data upon which to develop state programs on a sound basis.

Finally, this committee suggests that it remain a standing resource for state consultation regarding the impact and efficacy of educational programs and for updating and developing the educational system.

COORDINATOR OF PROGRAMS FOR PREVENTION OF MENTAL RETARDATION

The Committee respectfully urges the Governor to establish the position of Coordinator of Programs for Prevention of Mental Retardation and charge this person with this most important responsibility. The Coordinator must be able to facilitate the programs of existing state agencies and work comfortably with their personnel. He or she should bear primary responsibility for increasing awareness throughout the Commonwealth about retardation and its prevention, and this person must be able to effectively deal with a wide variety of involved persons. The exact organization in which the coordinator works should be left to the Governor's discretion, but the Committee feels that it is imperative that the chief executive have direct contact with this person since no single state department or agency can deal effectively with the multitude of opportunities which increased activity to prevent mental retardation poses.

APPENDIX A

I. Cost of representative current programs for the retarded

Annual financial cost
$2948 to educate a prodoundly multi-handicapped child in Hampton
$ 979 to educate a Educable Retardate in Richmond
$2106 to educate a Trainable Retardate in Richmond
$2866 to educate a multiple handicapped child in Richmond
$4000 first year (start up) costs to educate a mentally retarded child in Smyth County
$2000 to educate a midly to moderately retarded child in Charlottesville
$3000 to educate a profoundly retarded child with another handicap in Charlottesville
$6000 annual cost to hospitalize at Lynchburg Training School and Hospital

II. An example: Prenatal Detection of Mogolism
(Amniocentesis followed by abortion)

1500 Virginia women bear children after age 38
15 offspring of these mothers are mongols
8 survive beyond age one year
Virginia pays $200,000 to provide 40 years of institutional care for each survivor @$5,000 per annum
It would cost @$300,000 to screen the 1500 mothers over age 38 years and abourt the detected mongols
The contrasts to @$1,000,000 to provide 40 years of institutional care to the 8 surviving mongols

III. An example:

Virginia's screening treatment program for PKU cost @$38,000 per year. This contrasts to @$800,000 per year to provide institutionalization for PKU children had they not been diagnosed.

APPENDIX B

Additional items for review and consideration as suggested by Associations of Retarded Citizens (local, state and national).

Health education programs
Promotion of maternal health programs
Emphasis on improved obstetrical and pediatric services
Emphasis on expansion and improvement of case finding and disgnostic services
Emphasis on early diagnosis
Promotion of immunization programs
Management and prevention services for eradication of child abuse
Promotion of radiation control programs
Mass screening for identification of metabolic disorders and the establishment of appropriate treatment centers
Promotion of genetic counseling
Accident prevention
Elimination of lead and other environmental poisoning
Promotion of measures to overcome poverty-related causes of mental retardation
Emphasis on family planning

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