Every Child a Healthy Child

Report of the Select Committee for the Prevention of Developmental Disabilities

May 1985

Prepared By:

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Beth Austin of Greene, Maine, was diagnosed when a newborn as having phenylketonuria (PKU) through Maine's metobolic screening program. Now an active 7th grader, Beth is consistently on the honor roll, a member of the drama club, and a cross-country skier.

PKU, if not diagnosed and treated during infancy, leads to severe mental retardation.

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Maine Planning and Advisory Council on Developmental Disabilities

STATE OF MAINE
HOUSE OF REPRESENTATIVES
AUGUSTA, MAINE 04333

Kevin W. Concannon, Commissioner
Department of Mental Health
and Mental Retardation
State House
Augusta, Maine 04333

Dear Commissioner Concannon:

As Chairperson for the Select Committee for the Prevention of Developmental Disabilities, I am pleased to present to you the Committee's final report, "Every Child a Healthy Child."

At our first committee meeting on September 17, 1984, you challenged the committee to create a plan which would further Maine's efforts in reducing the number of children who are born with or who acquire a developmental disability. Since that time, the Select Committee has worked diligently to complete its task and has carefully considered various avenues leading to the reduction of developmental disabilities in Maine. If implemented, these recommendations which we submit to you will take an important step forward in reducing Maine's incidence of developmental disabilities to the lowest level possible.

New expenditures will be necessary in order to implement many of these recommendations. However, money spent on the prevention programs we have recommended will be recaptured through savings made by the reduced need for costly treatment and special educational services. But most importantly, savings in human suffering will be realized.

As a committee, we are pleased to have had this opportunity to participate in charting a positive course for Maine's children. We are hopeful that through your commitment to this effort the State Departments and the Legislature will take specific action to implement these recommendations.

Sincerely,

Merle Nelson

Merle Nelson
Chairperson

MN/dlc

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PREFACE

Society pays an extremely high price when children are born with a developmental disability or acquire a disability during childhood. Families face inordinate challenges and frustrations when their child has a disability. The cost of medical and habilitative treatment programs, of special educational programs, and of day care or residential care are staggering. Maine's Blue Cross/Blue Shield has reimbursed hospitals up to $118,000 for one infant's intensive care. In excess of $41 million was spent last year on special education in Maine. Maine's Medicaid program spent nearly $15½ million in diagnosing and treating children with health disorders and handicapping conditions. The costs for rehabilitation programs, adult day care programs, and life-long residential care for severely handicapped persons are enormous. We as citizens bear most of these costs through insurance premiums and local, state, and federal taxes.

Many developmental disabilities can be prevented. The Select Committee for the Prevention of Developmental Disabilities has thoughtfully considered various programs that could help to prevent developmental disabilities. The Committee has agreed upon 15 recommendations which, when implemented, will significantly reduce the incidence of developmental disabilities in Maine. Recommendations include (1) providing education--educating pregnant women about what they can do in order to improve their chances of having a healthy baby, educating physicians and nurses to keep them current with the state of the art of pediatric and obstetrical care to prevent developmental disabilities, expanding the prevention material in health professions education programs, and assuring that all Maine children receive comprehensive health education in their schools, (2) assuring specialty services to handicapped preschool children and identifying infants at risk for or with a handicapping condition, and (3) developing a system which will assure that services to prevent developmental disabilities are coordinated and financially supported.

By implementing the Select Committee's recommendations, Maine has an opportunity to reduce the need for costly treatment services for disabled persons, thereby recapturing the costs of prevention programs. Most importantly, the human suffering which occurs when a child has a developmental disability can be prevented.

INTRODUCTION

Maine's investment in programs to prevent developmental disabilities will result in inestimable savings to the state. Prevention programs can reduce the number of children needing costly treatment services, special education programs, and long-term care. They can also result in increased state revenues from the productivity of those citizens who otherwise will be unable to contribute to society. But most importantly, human suffering will be reduced. The long-term financial savings through prevention of developmental disabilities will more than pay for the cost of these programs.

The cost of treatment programs for the developmentally disabled are tremendous. Maine's Blue Cross/Blue Shield Insurance Company paid over $2,300,000 for intensive newborn care in 1984. There were 53 newborns covered by BC/BS who each required treatment costing in excess of $20,000. The average payment for these children was $44,016 and ranged up to $118,000.

In a study conducted in Rhode Island by Walker, et al. (1984), the costs for infants with a birth weight under 1,000 grams were determined. Hospital costs for those infants that survived ranged from $31,835 to $167,324 (in 1982 dollars). C. Arden Miller, M.D., University of North Carolina, states that $360 million per year nationally can be saved in neonatal intensive care and hospitalization costs if adequate prenatal care is provided to all women (Folkenberg 1984).

"The Nation's Health" (March 1985) recently reported that if preventive care would cut "the low birth weight rate in a high-risk group from 11.5 percent to over 10.76 percent, the program would be paid for by the savings on medical care that would be unneeded by babies born healthy. And, if the rate were cut to 9 percent, every dollar spent on parental care would save $3.38."

Maine's Crippled Children's Program served nearly 2,000 low-income children in fiscal year 1982, and $520,872 was spent for medical care costs alone for these children. Maine's Medicaid program spent nearly $15½ million in fiscal year 1983 on diagnosing and treating children with health disorders. Approximately two-thirds of those dollars were spent on children with a potential disability condition. For example, $3,162,837 was spent on children evaluated for or diagnosed with mental retardation, $1,471,088 for mental/emotional problems, and $943,733 for vision problems.

In the 1983-84 school year, 25,581 Maine children ages 3 to 21 years were identified by the Department of Educational and Cultural Services as handicapped. Maine schools spent in excess of $41 million in special education services for handicapped

children. Local communities pay for approximately forty-five percent of these costs.

The Bureau of Rehabilitation, Department of Human Services, spent nearly $2,900,000 in fiscal year 1984 for their rehabilitation program. They spent $563,800 for individuals with a diagnosis of mental retardation, $538,200 on mental illness, $309,800 on hearing disorders, and $298,800 on visual disorders.

For those severely and profoundly retarded individuals requiring residential care at an Intermediate Care Facility for the Mentally Retarded (ICF/MR), the cost is about $33,350 per individual per year. Most individuals in ICF/MR also attend day care programs at an average cost of $5,700 per individual per year. If an individual were admitted to an ICF/MR at age 20 years and remained there a lifetime, average 72 years, the cost would be over $2 million for that individual.

The costs for providing services to handicapped individuals are immense, yet essential. The cost in human suffering is extraordinary. Families experience ongoing trauma when a child with a handicapping condition is born. Families must cope with daily care; with not knowing what the future will bring for the child; with explaining to family, friends, and social acquaintances about their child's condition; with the disruption the child brings to the family including disappointment, guilt, anger, marital stress, and decreased career mobility; and with a child whose disability and treatment may be painful (American Association of University Affiliated Programs, 1983).

If just one infant in Maine is born with appropriate weight instead of being born with extremely low birthweight and if prevention programs can cause just three children to be born healthy rather than being born profoundly retarded and requiring life-long care, the yearly costs of providing the prevention programs recommended by the Select Committee for the Prevention of Developmental Disabilities will be recaptured.

Prevention programs do work. A General Accounting Office report (U.S. Comptroller General, 1977) found that the yearly cost for a metabolic screening program was less than one-eighth of the projected cost of caring for one impaired child over a lifetime. A study conducted in Texas found a savings of $8 for every $1 spent in vision and hearing screening, preventive dentistry, and early identification of congenital anomalies programs. They also found that it was cost-effective to conduct preventive education and counseling programs (Department of Health and Human Services, 1981).

Colorado found that for every dollar spent on prenatal care, they saved $11 that would have been spent on medical and special education needs of low birth weight infants (Colorado Developmental Disabilities Council, 1984).

The opportunity to prevent human suffering and to save millions of dollars for the State of Maine is at hand. Prevention technology is inexpensive and uncomplicated, simply a matter of education, screening, and early treatment. The time to act is now, and the Select Committee for the Prevention of Developmental Disabilities strongly urges the Governor of the State of Maine, the Legislature, and the private sector to commit the necessary resources to implement the following recommendations.

RECOMMENDATIONS

In October of 1983, the final report of a project to explore Preventing Developmental Disabilities in Maine was submitted to the Maine Council on Developmental Disabilities. This study, conducted by Medical Care Development, recommended that a highly visible statewide steering committee be formed to develop a plan and to secure funding for a statewide system of developmental disabilities prevention.

Members of the Select Committee for the Prevention of Developmental Disabilities were appointed by Commissioner Concannon, and six meetings were held between September 17, 1984, and January 30, 1985.

Under the guidance of Merle Nelson, State Representative, the Select Committee analyzed various program options for reducing the incidence of developmental disabilities in Maine. The recommendations were intended to provide the state with specific directions to be pursued and to identify precise actions to be taken. The Select Committee intends that this document will become the working plan for the Department of Mental Health and Mental Retardation, Department of Human Services, and Department of Educational and Cultural Services in their activities to prevent developmental disabilities.

For purposes of this report, the Select Committee used the national definition of developmental disabilities which is as follows:

A severe, chronic condition which:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments,

2. Is manifest before age 22,

3. Is likely to continue indefinitely,

4. Results in substantial functional limitations in three or more of the following areas of major life activity:

   --Self-care
   --Learning
   --Receptive and expressive language
   --Mobility
   --Self-direction
   --Capacity for independent living
   --Economic self-sufficiency

5. Reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are (a) of lifelong or extended duration, and (b) individually planned or coordinated.

I. PATIENT HEALTH EDUCATION:

RECOMMENDATION 1:

ASSURE THAT ALL PREGNANT WOMEN IN MAINE RECEIVE EARLY AND CONTINUOUS PRENATAL CARE AND HEALTH EDUCATION/COUNSELING BY:

A. INCREASING THE RATE OF MEDICAID REIMBURSEMENT FOR PRENATAL CARE,

B. DEVELOPING STANDARDIZED HEALTH EDUCATION/COUNSELING PROGRAMS FOR PREGNANT WOMEN AND NEW MOTHERS,

C. SECURING MEDICAID AND OTHER THIRD-PARTY COVERAGE FOR HEALTH EDUCATION/COUNSELING SERVICES FOR PREGNANT WOMEN, AND

D. DEVELOPING AND EXPANDING SPECIAL MODELS OF HEALTH EDUCATION/COUNSELING FOR WOMEN WHO DO NOT USE THE MEDICAL CARE SYSTEM.

Methodology:

1. Increase Medicaid reimbursement for prenatal care (antenatal care, vaginal delivery, and postpartum visit) by 50%, from the current rate of $268 to $402. Medicaid rates would still be far below the usual obstetrical charges which range from approximately $500 in northern Maine to $750 in the Portland area. Medicaid's billing procedures needs to be simplified for physicians who refer clients for specialty obstetrical care.

2. Develop standardized prenatal health education program. Ensure that the Department of Human Services supports a qualified team of physicians, nurses, and health educators to prepare a model prenatal education program and have the team with the assistance of trainers competent in conducting adult education training programs deliver regional training programs for professionals who would provide the standardized program. Develop the method of delivering health education which best suits the community needs. The primary physician's office, local hospital, local schools, the work place, and patients' homes should all be considered as possible sites for providing health education.

3. Develop through the Medicaid program a category of service for health education and counseling in order that professionals providing prenatal health education can receive reimbursement for their services.

4. Develop a similar standardized health education model for new mothers and their families. Provide new parents with information about caring for their infants which can prevent the occurrence of developmental disabilities, such as need for immunization, proper nutrition, accident prevention, normal growth and development, infant stimulation, and parent/infant relationships.

5. Assure that women less likely to use the medical care system such as teens and low-income women, receive appropriate health education and counseling services. A variety of services should be available and should include:

    a. Support groups.

    b. Individual home-based services such as those of public health nursing or Adolescent Pregnancy Coalition projects.

    c. In-school primary health care services developed with consultation from local physicians as a demonstration project modeled after a project in St. Paul, Minnesota. The services would include school physicals, weight reduction consultation,

family planning consultation, and prenatal care. The St. Paul project found that the fertility rate for the school fell from 79 births per 1,000 to 35 per 1,000 and that the dropout rate due to pregnancy was reduced from 45% to 10% in the three years following the institution of the school clinic (Edwards, et al., 1980).

d. A health education program targeted for working women who are pregnant to be provided at the worksite. The program should include information on nutrition, hypertension, diabetes, and lifestyle management during pregnancy.

Estimated Cost:

1. Effective prenatal education and counseling: $250,000 per year for three years to develop the system; $800,000 per year for provision of service to all pregnant women (third-party payors).

2. Increase in Medicaid rate for prenatal care by 50%: $330,000 per year cost to Medicaid.

3. Education for new mothers: $100,000 per year for three years to develop system; $400,000 per year to provide education.

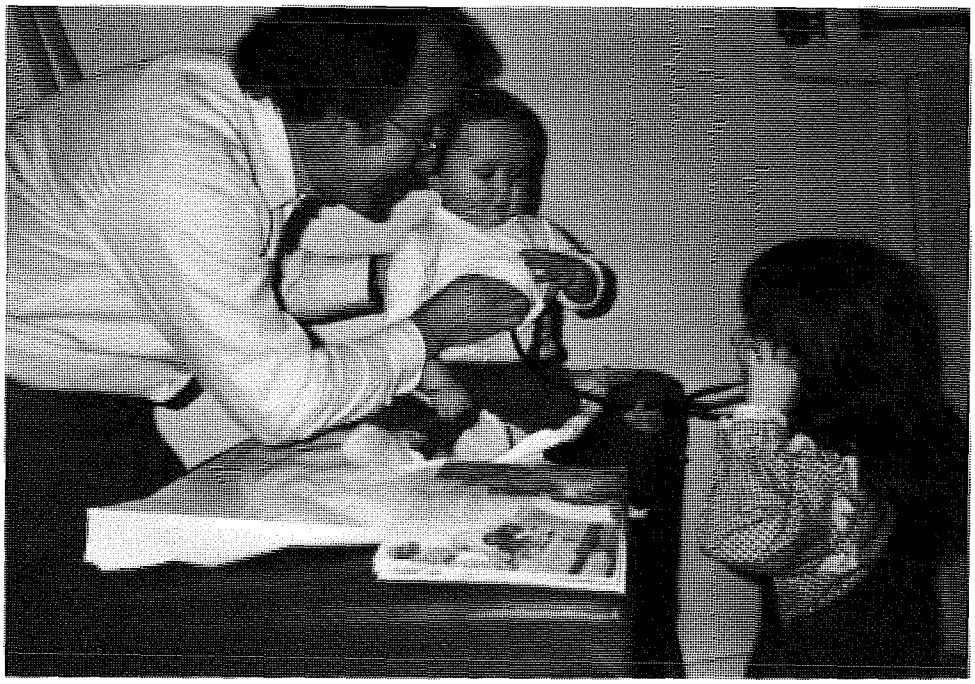
4. Program for hard-to-reach pregnant women: $200,000 per year for five regional coordination and case finding programs.

Rationale: Fewer babies will be born with developmental disabilities if all pregnant women in Maine seek early and continuous prenatal care so that pregnancy problems can be found and treated early. Many pregnant women have special needs due to their limited financial resources and, as often is the case, their lack of education and family support. Physicians need to be provided with incentives for delivering the more intensive services Medicaid women need. Family practitioners, who see the majority of Medicaid women, need not only an increase in their payment for services provided but also need an incentive to refer clients to specialty obstetrical care when needed. This can be accomplished by simplifying the billing requirements when a client is transfered. It is estimated that over half of Maine's obstetricians do not accept Medicaid clients. The perinatal study commissioned by the Department of Human Services found that 46% of non-Medicaid clients received prenatal services from an obstetrician, whereas only 28% of Medicaid clients receive prenatal care from an obstetrician (McDonald, 1984). A national survey showed that OB/GYN specialists are among the least likely specialists to accept Medicaid clients. Other studies show that OB/GYN specialists will increase their participation in the Medicaid program when reimbursement rates are increased (Mitchell and Schurman, 1984).

Fewer babies will be born with a developmental disability if all pregnant women in Maine understand what they can do to improve their chances of having a healthy baby. All pregnant women should be aware of the risks to their unborn baby if they smoke, drink, or take drugs. They should know about the importance of good nutrition, the need to seek early and continuous prenatal medical care, and risks of having a child with a genetic disease. Quality health education/counseling must be provided to all pregnant women. To be made widely available, education must be specifically reimbursed by Medicaid and other third-party insurance providers. The increased knowledge and counseling support will help women make critical decisions during their pregnancy.

Many women in Maine choose not to participate in the mainstream medical care system. For these women, special models of delivering health education must be developed which can most effectively be accomplished through regional programs of coordination, care finding, and program development.

II. HEALTH EDUCATION FOR PROFESSIONALS:



RECOMMENDATION 2:

PROVIDE CONTINUING EDUCATION RELATED TO THE PREVENTION OF DEVELOPMENTAL DISABILITIES FOR MAINE'S PHYSICIANS, NURSES, AND OTHER HEALTH PROFESSIONALS WHO WORK WITH MOTHERS, INFANTS, AND CHILDREN.

Methodology:

1. Develop a model of continuing education for Maine's physicians in conjunction with appropriate medical academies. Design the model to reach physicians in their communities, hospitals, and offices. (See pages 32-35 for continuing education curriculum developed by the Physician Education Subcommittee.)

2. Use the physician education model as a guide in developing continuing education for nurses and other health professionals.

3. Educate staff of neonatal intensive care units (NICU) about community resources which can help facilitate the transition of high-risk newborns from hospital to community. Wheelock College's "Project Welcome" program will be conducted at Maine Medical Center to educate NICU staff about the need for community referral when transferring infants. This program should be expanded beyond Maine Medical Center to include Level II neonatal units in Maine.

4. Establish a clearinghouse and technical assistance center to provide health professionals with current literature and materials which will assist them in expanding their knowledge and their services related to prevention of developmental disabilities. The center would be a resource where professionals could turn for the most current and complete information on developmental disabilities prevention.

Cost: The Department of Human Services currently has available $150,000 per year for funding physician and nursing continuing education through grants or contracts to health agencies or institutions. To assure ongoing funds for education in such topics as principles of genetic counseling, prenatal care for high-risk women, and prevention of prematurity, funds should be sought through a variety of sources including insurance companies. The Departments of Human Services and Mental Health and Mental Retardation should financially support a clearinghouse either in-house or through a grant to an educational organization.

Rationale: If physicians, nurses, and other health professionals are to keep current with the rapidly changing state of the art of preventing developmental disabilities, continuing education must be made available to them. Health professionals must be kept informed about new technology available in prenatal diagnosis, in effective methods of positively influencing patients' behavior during their pregnancies, in working with high-risk patients, and in other methods of preventing developmental disabilities.

Having a high-risk infant in a neonatal intensive care center can be a time of crisis for families. Assuring good communication between neonatal unit, family, and primary physician, especially at the time of the infant's discharge, can ease family stress.

RECOMMENDATION 3:

EXPAND MATERIAL ON PREVENTING DEVELOPMENTAL DISABILITIES IN THE CURRICULA OF MAINE'S HEALTH PROFESSIONS EDUCATION PROGRAMS AT THE UNDERGRADUATE, GRADUATE, AND POST-GRADUATE LEVELS.

Methodology:

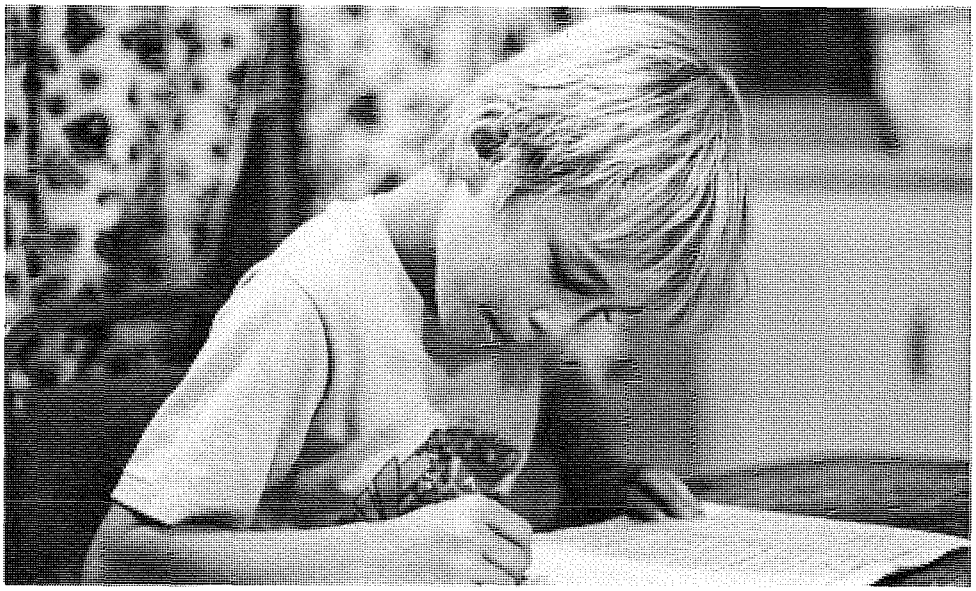
1. Review the curricula from all of Maine's schools of nursing, family practice and obstetrical residency programs, medical school, and occupational and physical therapy programs related to developmental disabilities prevention.

2. Identify the strengths and weaknesses related to information and practice skills for prevention of developmental disabilities in such curricula. Assist programs with developing or expanding their prevention curriculum.

Estmated Cost: A knowledgeable professional team of consultants and a lead staff person with office support would be needed for two years at an approximate cost of $50,000 per year.

Rationale: If the health professionals' knowledge and skills of preventing developmental disabilities are to be elevated, it is essential that students in health professional educational programs gain a concrete basis of knowledge in developmental disabilities prevention. Currently, higher education programs vary in their emphasis on developmental disabilities prevention. If higher educational curricula are to be changed, special assistance must be provided to curricular planners who are consistently faced with more possible curricular material than course time will allow.

III. HEALTH EDUCATION FOR ELEMENTARY AND HIGH SCHOOL STUDENTS:



RECOMMENDATION 4:

EXPAND AND DEFINE COMPREHENSIVE HEALTH EDUCATION IN SCHOOLS TO INCLUDE COMMUNITY HEALTH, CONSUMER HEALTH, ENVIRONMENTAL HEALTH, FAMILY LIFE, GROWTH AND DEVELOPMENT, NUTRITIONAL HEALTH, PERSONAL HEALTH, PREVENTION AND CONTROL OF DISEASE AND DISORDERS, SAFETY AND ACCIDENT PREVENTION, AND SUBSTANCE ABUSE PREVENTION, WITH A FOCUS ON PREVENTION OF DEVELOPMENTAL DISABILITIES IN EACH OF THESE AREAS.

Methodology:

Encourage the School Approval/Accreditation Task Force to approve the comprehensive definition of health education as developed by the Department of Educational and Cultural Services. This process will require schools to provide a comprehensive health education curriculum to meet Department of Educational and Cultural Services' approval or accreditation requirements and will require schools to clearly differentiate health education from physical education.

Estimated Cost: No new funds are required.

Rationale: Assuring that all students receive basic yet comprehensive health education in all grades will provide a foundation for each student in making important future life decisions about pregnancy and parenthood. With increased knowledge these prospective parents will be better able to avoid hazards and increase their chances of bearing and raising healthy children.

RECOMMENDATION 5:

ENSURE THAT COORDINATION OF THE EXISTING SCHOOL HEALTH EDUCATION INITIATIVES OCCURS AND ENSURE THAT THE DEPARTMENTS OF EDUCATIONAL AND CULTURAL SERVICES, HEALTH AND HUMAN SERVICES, AND MENTAL HEALTH AND MENTAL RETARDATION ALLOCATE FUNDING FOR SCHOOL HEALTH EDUCATION PROGRAMS THAT RELATE TO THE PREVENTION OF DEVELOPMENTAL DISABILITIES.

Methodology:

1. Recommend that coordination among the existing school health education programs occurs through the health education consultants of the Department of Educational and Cultural Services.

2. Have the Interdepartmental Committee advise the Legislature about the level of funding for the Departments of Educational and Cultural Services, Human Services, and Mental Health and Mental Retardation in supporting school health education.

Estimated Cost: No additional costs will be incurred.

Rationale: There are several health education curricula available from various departments and agencies. Among these curricula are Family Life Curriculum and Dental Health from the Department of Human Services and the Alcohol and Drug Abuse Program from the Department of Educational and Cultural Services. These programs are offered to schools independent of each other. By coordinating programs, schools will have a simplified process of obtaining information and assistance to implement curricula.

RECOMMENDATION 6:

ASSURE THAT TEACHERS ARE ADEQUATELY PREPARED TO TEACH HEALTH EDUCATION BY:

A. PROVIDING SEPARATE DEGREE PROGRAMS FOR PHYSICAL EDUCATION AND HEALTH EDUCATION THROUGH THE UNIVERSITY OF MAINE, AND

B. REQUIRING THAT ELEMENTARY AND SPECIAL EDUCATION TEACHERS RECEIVE A HEALTH EDUCATION METHODS COURSE AS PART OF THEIR DEGREE PROGRAM.

Methodology:

1. Eliminate the dual health and physical education programs and replace them with separate health education and physical education programs.

2. Require through the State Board of Education that all elementary and special education teachers take a health education methods course in order to be certified.

3. Provide continuing education for teachers currently employed.

Estimated Cost: No new funds are required.

Rationale: In order for schools to ensure a quality comprehensive education program, there must be adequate teacher preparation. In the next several years Maine will realize a two-thirds turnover of teachers due to retirement. Now is an excellent time to institute changes in teacher preparation requirements to assure that the next generation of teachers will be prepared to teach health education.

RECOMMENDATION 7:

CONDUCT A DEMONSTRATION IN-SCHOOL NURSERY/CHILD CARE SERVICE.

Methodology:

Implement recommendations 6 and 7 of the Maine Child Care Task Force in their publication Child Care in Maine: An Emerging Crisis (1984) which are as follows:

"6. That the Department of Educational and Cultural Services amend legislation and develop policy or other action outlining public school involvement in child care arrangements to include but not be limited to:

--The use of school space and transportation for child care.

--Encouragement of the development and implementation of community schools.

--Assisting pregnant students and teen parents in continuing their education and meeting their child care needs.

--Facilitating the provision of child care for participants in both day and evening Adult Education Programs.

7a: That the Department of Educational and Cultural Services sponsor pilot projects--in both rural and urban localities--to develop school-run preschool and school-age child care programs. These projects can be experimentally funded through the state subsidy for education formula.

7b: That the Department of Educational and Cultural Services study the feasibility of including space for child care in any school construction project."

Estimated Cost: The cost of a single in-school nursery demonstration model will be approximately $50,000 per year.

Rationale: A nursery/child care service within the school will provide a laboratory where parenting education can occur for all students and will provide needed day care services.

RECOMMENDATION 8:

PROMOTE AND PROVIDE INCENTIVES FOR TEENAGE DRIVERS TO PARTICIPATE IN PROVEN SAFETY PROGRAMS SUCH AS THE DEFENSIVE DRIVING COURSE AND INCENTIVES TO ENCOURAGE THE USE OF AUTOMOBILE AND MOTORCYCLE SAFETY EQUIPMENT SUCH AS SEAT BELTS, CHILD AUTO SAFETY SEATS, AND HELMETS. SUPPORT LEGISLATION MANDATING SEAT BELT USE.

Methodology:

1. Have the Governor direct the Superintendent of Insurance and Department of Educational and Cultural Services to take specific action to promote and enhance effective driver safety programs. Have the Superintendent of Insurance and Department of Educational and Cultural Services work directly with the insurance industry to develop incentives for young drivers to participate in these programs.

2. Support the passage of legislation mandating use of seat belts through lobbying and advisory groups interested in developmental disabilities prevention.

Estimated Cost: No new costs will be incurred by this activity.

Rationale: Individuals between ages 15 years and 24 years have the highest automobile-related fatality and injury rate of all ages. In 1983, 42% of fatal auto accidents and 43% of injuries were to individuals 15 to 24 years old. To address the problem of developmental disabilities resulting from auto injuries, it is recommended that programs which increase the skill and safety of young drivers be promoted and expanded.

It has been clearly shown that seat belt use reduces the incidence of fatality and severe injuries. Requiring everyone to use auto seat belts will result in fewer disabling injuries to children and adolescents; therefore, developmental disabilities will be reduced. Children will also learn good buckling-up habits when they see parents using their seat belts.

IV. HEALTH EDUCATION FOR THE PUBLIC:

RECOMMENDATION 9:

DEVELOP A LONG-RANGE PUBLIC EDUCATION CAMPAIGN INCLUDING:

A. PUBLICIZING THE CAUSES AND CONSEQUENCES OF DEVELOPMENTAL DISABILITIES TO GENERATE PUBLIC SUPPORT AND UNDERSTANDING OF PREVENTION EFFORTS, AND

B. EDUCATING THE PUBLIC ABOUT THE NEED FOR EARLY PRENATAL CARE AND THE EFFECTS OF ALCOHOL CONSUMPTION, DRUG USE, AND SMOKING DURING PREGNANCY.

Methodology:

1. Have the Commissioners of the Departments of Human Services, Educational and Cultural Services, and Mental Health and Mental Retardation develop a joint media campaign and assure that it is carried out. A five-year plan should be designed to assure concentrated and continuous public education on this matter.

2. Involve private agencies and organizations such as the March of Dimes and the Maine Lung Association who are providing public education in this area in the development of a public media campaign.

Estimated Cost: The cost of developing one 30-second public service announcement (PSA) is approximately $500 plus staff time needed to produce and market the PSA. At least four PSA's should be produced and aired per year at a cost of $2,000.

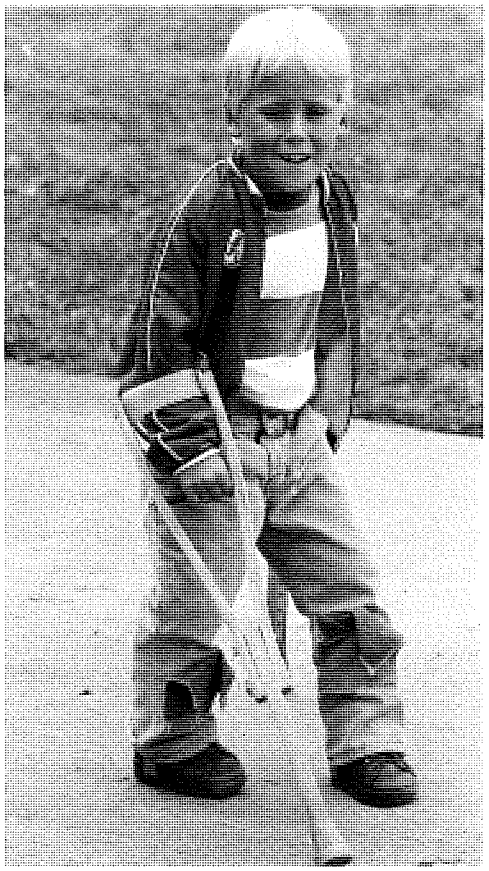
Rationale: Fetal Alcohol Syndrome (FAS) is believed to be the third most common cause of mental deficiency. Smoking during pregnancy is associated with low birth weight infants (Davidson, 1981). In 1981 the Surgeon General's Advisory on Alcohol and Pregnancy, advised pregnant women to abstain from alcoholic drinks (Rosett and Weiner, 1982). Developmental delays caused from excessive use of alcohol, tobacco, or other teratogenic drugs can be totally prevented if women abstained from use of these items prior to and during their pregnancies.

The public must be educated about the causes and consequences of developmental disabilities to assist in avoiding these disabilities in their own families and to create greater public support for prevention services.

V. SPECIAL SERVICES AND DEMONSTRATION PROJECTS:

RECOMMENDATION 10:

INCREASE FUNDING FOR PRESCHOOL PROJECTS TO ASSURE THAT CHILDREN WITH DEVELOPMENTAL DISABILITIES FROM BIRTH TO AGE FIVE AND THEIR FAMILIES RECEIVE NEEDED SPECIALTY SERVICES SUCH AS FAMILY COUNSELING AND SUPPORT SERVICES, OCCUPATIONAL THERAPY, PHYSICAL THERAPY, SPEECH AND LANGUAGE THERAPY, AND MENTAL HEALTH SERVICES.



Methodology:

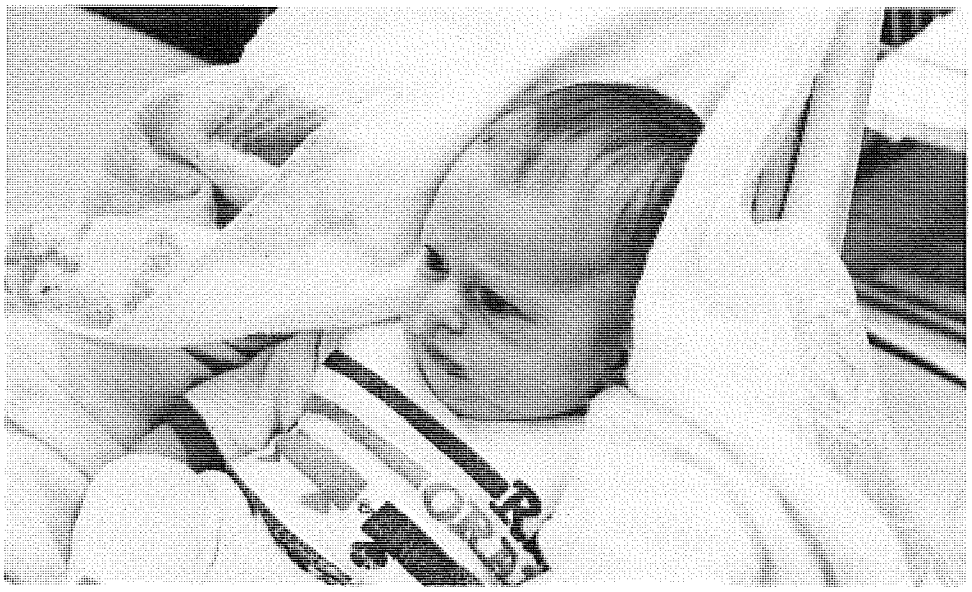
Expand specialty services for preschool handicapped children and their families. Include in these services family counseling and support services which assist parents in dealing more effectively with their child and help prevent family disruption.

Estimated Cost: The Department of Mental Health and Mental Retardation would require $240,000 to support additional family counselors in their six regional offices. The amount of funds needed for support of other direct services should be determined by the Interdepartmental Coordinating Committee for Preschool Handicapped Children.

Rationale: Many children who are developmentally disabled can improve their chances of having a successful school experience if needed specialty services are provided to them as early in life as possible. Families need professional support in order to interact more effectively with their child and to help them use the professional community system. Family counselors can also assist families in seeking professional help to avoid developmental disabilities in future children.

The State of Colorado conducted a study which found that substantial taxpayer money could be saved if early intervention was provided to handicapped preschoolers. The cost of providing early intervention services was less than the cost of providing special education services during the elementary years. Colorado found that over a period of three years they saved $1,560 per handicapped student and $1,050 per at-risk student (Colorado Developmental Disabilities Council, 1984).

RECOMMENDATION 11:



SUPPORT THE EFFORTS OF THE INTERDEPARTMENTAL COORDINATING COMMITTEE IN DEVELOPING A COMPREHENSIVE STATEWIDE PREVENTIVE INTERVENTION PLAN FOR IDENTIFICATION, EVALUATION, AND REFERRAL SERVICES FOR CHILDREN FROM BIRTH TO THREE YEARS AT RISK OF DEVELOPMENTAL DISABILITIES.

Methodology:

1. Conduct an evaluation of the current preventive intervention projects.

2. Support Recommendation #1 of the Commission to Examine the Availability, Quality, and Delivery of Services Provided To Children with Special Needs to expand the preventive intervention projects designed to identify infants with or at risk of a developmental disability.

Estimated Cost: According to the Maine Commission to Examine the Availability, Quality, and Delivery of Services (1984), costs to provide these services statewide is estimated at $3 million.

Rationale: The earlier that children with a known developmental disability or children at risk for one are found and the earlier appropriate intervention services can be initiated, the greater the chances are that the disability can be ameliorated or prevented. Three preventive intervention projects will be operational by July 1985. These projects are designed to identify, during the newborn hospital stay, infants who are environmentally or physically at risk or who have an identified biological handicap and then to orchestrate the provision of needed services through the coordinated efforts of local resources.

RECOMMENDATION 12:

IMPROVE THE NUTRITIONAL STATUS OF PREGNANT WOMEN AND CHILDREN THROUGH INCREASING THE ENROLLMENT IN THE WOMEN, INFANTS, AND CHILDREN'S PROGRAM (WIC) BY EXPANDING THE ACCESSIBILITY OF THE WOMEN, INFANTS, AND CHILDREN'S PROGRAM THROUGH THE DEVELOPMENT OF NEW METHODS OF PROVIDING WIC SERVICES AND BY INCREASING OUTREACH EFFORTS.

Methodology:

1. Conduct a demonstration project which creates a cooperative arrangement between primary care physicians and the local WIC agency in delivering WIC services. This project would maximize the use of the physician in providing WIC services by involving them in activities such as intake, certification, and the provision of vouchers/checks.

2. Require that state-supported well child clinics and WIC services be provided concurrently.

3. Increase outreach efforts including airing of informational public service messages.

Estimated Cost: Present WIC funding will permit expanded use of the WIC program.

Rationale: The Maine WIC Program serves approximately 26% of individuals eligible for services. It is expected that WIC enrollment could be increased by making services more accessible to clients and by making eligible families more aware of WIC services.

VI. IMPLEMENTATION OF THE SELECT COMMITTEE RECOMMENDATIONS:

RECOMMENDATION 13:

HAVE THE DEPARTMENT OF HUMAN SERVICES, DEPARTMENT OF EDUCATIONAL AND CULTURAL SERVICES, AND DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION DEVELOP A COORDINATED EFFORT TO IMPLEMENT THE RECOMMENDATIONS OF THE SELECT COMMITTEE FOR THE PREVENTION OF DEVELOPMENTAL DISABILITIES AND PROVIDE AN ANNUAL REPORT OF ACTIVITIES TO THE GOVERNOR AND THE LEGISLATURE.

Methodology:

1. Form a joint legislative committee of the Human Resources Committee and Education Committee to address developmental disabilities prevention and child health issues.

2. Inform the Governor and Legislature about the work of the Select Committee.

3. Require the Departments of Mental Health and Mental Retardation, Human Services, and Educational and Cultural Services to develop a joint developmental disability prevention service plan and to submit annual progress reports to the Governor and to the joint legislative committee.

Estimated Cost: No new funds are needed.

Rationale: It is imperative that the recommendations of the Select Committee not be shelved and forgotten if progress toward the reduction of developmental disabilities in Maine is to occur. Top government officials must become informed and involved in prevention of developmental disability efforts in order to assure continued focus on the problem of developmental disabilities.

RECOMMENDATION 14:

DEVELOP AN EVALUATION SYSTEM TO MEASURE THE IMPACT OF EACH PREVENTION PROGRAM AND THE TOTAL PREVENTION EFFORT IN MAINE.

Methodology:

1. Have the Departments of Mental Health and Mental Retardation, Human Services, and Educational and Cultural Services and other appropriate agencies develop an evaluation system concurrent with the interdepartmental developmental disabilities prevention action plan.

2. Require the Departments to include a provision for independent evaluation in all grants or contracts awarded by them related to the prevention of developmental disabilities.

3. Use the birth and death reporting system, the hospital discharge data system, and other health data reporting systems to define the incidence of developmental disabilities to whatever extent possible for the purpose of conducting research into causes and for evaluating prevention programs.

4. Explore the possibility of developing an identification and tracking system for infants and children with a known developmental disability and, as appropriate, remove any legal restrictions on developing a tracking system.

5. Develop a substantial long-term evaluation/research project to explore the causes of developmental disabilities and to identify effective preventive methods.

Estimated Cost: A start-up cost of $30,000 would be needed to develop a basic evaluation system. To conduct a longitudinal impact evaluation of the success of the preventive efforts in Maine would require $100,000-200,000 per year.

Rationale: In order to secure additional as well as continued funding for prevention of developmental disabilities services, it is imperative that the effectiveness of existing programs be demonstrated. It is also important to target the scarce available funds to those services most effective in preventing developmental disabilities. An evaluation system developed as an integral part of the prevention program should produce vital information for the purposes of securing and targeting funds.

An overall evaluation of the activities of the prevention of developmental disabilities in Maine is possible if a data system

is developed using Maine's vital statistics information and Maine's hospital discharge information. The incidence of developmental disabilities by cause must be identified. Trends in incidence can then be followed from year to year.

Developing a tracking system for individuals with a known disability can assist those individuals by assuring that appropriate services are provided and can generate important information about the long-term impact of specific services.

Maine is an ideal state in which to conduct a comprehensive evaluation/research project. Maine's population is small, Maine's professionals comply well with reporting of vital statistics and hospital discharge, and Maine has an effective newborn regionalization/referral system. All these factors are important in designing and carrying out a research project. Maine also has an extremely low infant mortality rate compared to the nation. This is an unusual phenomena given Maine's overall low socioeconomic status. National funders should be eager to discover the reasons for Maine's low infant mortality rate.

RECOMMENDATION 15:

ENCOURAGE A COORDINATED EFFORT, WITH PARTICIPATION FROM BOTH THE PRIVATE SECTOR AND STATE GOVERNMENT, TO SUPPORT THE TARGETING OF FEDERAL AND STATE FUNDS FOR SERVICES TO PREVENT DEVELOPMENTAL DISABILITIES.

Methodology:

1. Form a coalition for the prevention of developmental disabilities to unite agencies and organizations interested in prevention activities.

2. Have the coalition lobby for state and federal funding to increase support for prevention of developmental disabilities activities. Have the coalition work with both state legislators and Maine's congressional leaders in Washington.

3. Have the Select Committee for the Prevention of Developmental Disabilities serve as a nucleus for a broad-based advocacy movement.

Estimated Cost: $25,000 per year would be required to support staff and committee costs.

Rationale: Advocacy for the prevention of developmental disabilities should be developed in order to lobby for new, secure funding for developmental disabilities prevention services.

(After Deadline)
FIRST REGULAR SESSION

ONE HUNDRED AND TWELFTH LEGISLATURE

Legislative Document No. 1385

H.P. 964 House of Representatives, April 25, 1985

Approved for introduction by a majority of the Legislative Council pursuant to Joint Rule 27.

Reference to the Committee on Human Resources suggested and ordered printed.

EDWIN H. PERT, Clerk

Presented by Representative Nelson of Portland.

Cosponsored by Senator Pearson of Penobscot, Representative Murphy of Kennebunk and Speaker Martin of Eagle Lake.

STATE OF MAINE

IN THE YEAR OF OUR LORD
NINETEEN HUNDRED AND EIGHTY-FIVE

AN ACT to Prevent Developmental Disabilities in Maine.

Be it enacted by the People of the State of Maine as follows:

Sec. 1. 22 MRSA c. 962 is enacted to read:

CHAPTER 962

PREVENTION OF DEVELOPMENTAL DISABILITIES

§3571. Prevention of developmental disabilities

1. Prevention of developmental disabilities; Department of Human Services. The Department of Human Services shall serve as the principal agency for the primary prevention of developmental disabilities in the State and shall provide services for pregnant women and new mothers to minimize the likelihood of their having a developmentally disabled child. In

particular, the department shall conduct professional education to assure that the best available prevention techniques are utilized by health care professionals in the State and shall assure that access to prenatal services exists for all women of childbearing age in the State.

2. Counseling and support services; Department of Mental Health and Mental Retardation. The Department of Mental Health and Mental Retardation shall institute programs of family counseling and support services for families with developmentally disabled children aged 0 to 5 years. The purpose of these counseling and support services shall be to increase the family's understanding of the child's special needs and to enhance family members' abilities to cope with the physical and emotional strains experienced by families with handicapped children.

3. Preschool coordination projects; Department of Educational and Cultural Services. The Department of Eduational and Cultural Services through the preschool coordination projects shall assure the provision of comprehensive developmental services, including physical therapy, speech and language therapy and occupational therapy to preschool handicapped or delayed children. To the maximum extent possible, these programs shall make use of existing 3rd party payors and coordinate services with local resources. In instances where needed services are not available, the department shall use authorized funds to enable preschool coordination projects to work with local providers, including public and private agencies and school units to develop new or expand existing service to meet these needs.

In addition, the Department of Educational and Cultural Services shall assure that comprehensive health educational programs are available in state schools and that teacher training programs in the State include preparation in conduct of health educational programs.

§3572. Use of private agencies to deliver services

Private agencies shall be used as appropriate to carry out the implementation of initiatives to pre-

vent developmental disabilities in cooperation with the respective departments so that State Government agencies do not duplicate existing resources in the community and so that all available resources are used effectively to rapidly achieve the goal of preventing developmental disabilities in the State.

§3573. Reporting

The Department of Human Services, Department of Mental Health and Mental Retardation and Department of Educational and Cultural Services shall by January of each year submit a joint report to the joint standing committee of the Legislature having jurisdiction over human resources regarding the prevention activities conducted over the past fiscal year, plans for the succeeding year and a report on the incidence rate of births of developmentally disabled children in the State.

Sec. 2. Appropriation. The following funds are appropriated from the General Fund to carry out the purposes of this Act.

	1985-86	1986-87
HUMAN SERVICES, DEPARTMENT OF		
Bureau of Health		
All Other	$50,000	$50,000
These funds are to provide for the education of health professionals to improve prevention practices, including continuing education of physicians in perinatal care and for increasing training for family practice residents, nursing students and allied health professions' students in ways to prevent developmental disabilities.		

Bureau of Health		
All Other	$25,000	$25,000
These funds are to develop a statewide media campaign to encourage prevention behavior by pregnant women, including seeking prenatal care early in pregnancy.		
Bureau of Health		
All Other	$30,000	
These funds are to design an evaluation system, including a data system for evaluating the impact of prevention program on the prevalence of developmental disabilities in Maine.		
Bureau of Health		
All Other	$20,000	
These funds are to support pilot projects in child care education for teenage women.		
DEPARTMENT OF HUMAN SERVICES		
TOTAL	$125,000	$75,000
EDUCATIONAL AND CULTURAL SERVICES, DEPARTMENT OF		
Division of Special Education		
All Other	$75,000	$75,000

These funds are to provide funds to expand the preschool coordination projects for direct services, such as physical therapy, speech and language therapy and occupational therapy for preschool developmentally disabled children and their families.		
DEPARTMENT OF EDUCATIONAL AND CULTURAL SERVICES		
TOTAL	$75,000	$75,000
MENTAL HEALTH AND MENTAL RETARDATION, DEPARTMENT OF		
Office of Children's Services		
All Other	$75,000	$75,000
These funds are to provide for establishment of a program of family counseling and support services for families with developmentally disabled children age 0 to 5 years to minimize the long-term severity of the disability. This program will be carried out through the Preschool Handicapped Coordination Programs.		
DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION		
TOTAL	$75,000	$75,000

TOPICS FOR OBSTETRICIANS AND FAMILY PRACTITIONERS:

I. Prenatal Detection of Developmental Disabilities:

A. Serum AFP screening

B. Gestational timing in early pregnancy and indications for mid-trimester amniocentesis

C. Chorionic villus sampling

D. Indications for ultra-sound, x-ray, fetoscopy and amniography

II. Management of Pregnancy with Maternal Disease:

A. Diabetes mellitus, kidney or heart disease, maternal PKU, toxemia, herpes

B. Use of Level II and Level III resources

III. Safe and Acceptable Alternatives to Home Birth:

A. Complications of home birth

B. Birthing rooms and birthing centers

C. What is it families want and need?

D. Midwives and their supervision

IV. Management of Complicated Labor and Delivery:

A. Recent advances in indications for electronic monitoring and use of forceps

B. Breech deliveries; placenta praevia and abruptive

C. Indications for C-Section, variation in C-Section rates

D. Use of Level II and Level III resources for consultation and transport

TOPICS FOR PEDIATRICIANS AND FAMILY PRACTITIONERS:

I. Stabilization and Transport of Premature, Small for Gestational Age, and Sick Newborns:

A. Level I and Level II resources; regional network

B. Prevention and management of intracranial hemorrhage, hypoglycemia, and hypoxia

C. Early diagnosis of neonatal sepsis/meningitis

II. Health Supervision and Prevention of Developmental Disabilities:

A. Nutrition education; mental health promotion (Brazelton)

B. Support services for new family; parent groups

C. Accident and poisoning prevention; timing and techniques of patient education

D. Office screening for deafness, vision impairment, mental retardation, and cerebral palsy

E. Identification of syndromes--fetal alcohol, fragile X, Prader-Willi, etc.

F. Management of mild delays without causing family anxiety

G. Referral resources; child-find program of schools

III. Post-Discharge Follow-Up of High Risk Newborns and Early Intervention for Biological High-Risk Infants:

A. Effects of NICU stimulation (human and technical)

B. Coordination with Public Health Nurse

C. Early intervention resources in the community--referrals, communication links

D. Effectiveness of early intervention on the child, family

IV. Early Intervention for Environmental and Established High Risk Infants:

A. Risk assessment; maternal infant bonding

B. Abuse and neglect identification; community resources

C. Referral process; Child Protective Services

D. Epidemiology of developmental disabilities in poverty children; 0-3 programs; Head Start

E. Intervention for Down's syndrome, cerebral palsy, hearing impaired

F. Family involvement

TOPICS FOR OBSTETRICIANS, FAMILY PRACTITIONERS, AND PEDIATRICIANS:

I. Principles of Genetic Counseling:

A. Recurrence risks of chromosome, single gene, and polygenic disorders; e.g.:

--Down's Syndrome
--Translocations
--Fragile X
--PKU
--Congenital Hypothyroidism
--Neural Tube Defects
--Cleft Lip or Palate

B. Resources (local and state) for genetic counseling and referral indications and procedures.

II. Preconception and Prenatal Care of High-Risk Women in Poverty and Teenagers:

A. Effective and acceptable contraceptive techniques

B. Relating to teenagers and women in poverty

C. Patient education and nutrition counseling--use of office staff and third-party billing for patient education

D. Encouraging support groups and access to community resources

E. Office to hospital communication

III. Effects of Alcohol and Smoking in Pregnancy:

A. Epidemiologic studies

B. Establishing the diagnosis

C. Patient education techniques

D. Effective treatment programs--office-based, community-based

IV. Prevention of Prematurity:

A. Possible causal factors:

--Infection
--Intercourse
--Premature rupture of membranes

B. Management of pregnancy with poor previous outcome:

--Multiple spontaneous abortions
--Previous premature deliveries

C. Patient education to recognize signs of early labor; use of tocolytic agents

V. Trends in Neonatal Mortality and Morbidity--1960-1985:

A. Epidemiology of major and minor handicaps in U.S., Sweden, and elsewhere

B. Expected growth and development of NICU "graduates"

C. Effectiveness and use of regionalized perinatal care

VI. Management of Asphyxia in Fetus and Newborn:

A. Physiology

B. Resuscitation techniques

C. Management of meconium aspiration

DESCRIPTION OF RESOURCE ORGANIZATIONS REFERRED TO IN THIS REPORT

Adolescent Pregnancy Coalition Projects: Nine projects serve Maine's pregnant adolescents and new adolescent parents. The services vary to meet community and regional needs, but are primarily counseling, education, and assistance with obtaining medical and social services.

Interdepartmental Committee (IDC): The IDC is comprised of the Commissioners of the Departments of Human Services, Mental Health and Mental Retardation, Educational and Cultural Services, and Corrections and was formed to address the coordination of services provided by the departments.

Interdepartmental Coordinating Committee for Preschool Handicapped Children (ICCPHC): The committee with representatives from the Departments of Educational and Cultural Services, Mental Health and Mental Retardation, and Human Services; parents; and other agencies is responsible for planning and monitoring the Preschool Projects.

Preschool Projects: The Preschool Projects are designed to identify all children age three to five years old who are handicapped or who would require special educational services at school and to coordinate intervention services for those children. Sixteen projects provide statewide services.

Preventive Intervention Projects: These hospital-based projects are designed to identify infants with a health problem or at risk of a health problem and to coordinate local intervention services to the families. The projects are based in Norway, Machias, and Waterville.

Project Welcome: Provided through Wheelock College in Boston, the project conducts education to the staff of neonatal intensive care centers regarding both family and infant needs when transfering high-risk infants to their community.

Women, Infants, and Children (WIC): WIC is a federally funded food supplemental program designed to provide nutritious foods (primarily dairy products) to eligible pregnant and breastfeeding women and to infants and children up to age five. WIC also provides nutrition education to these families.

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Vice Chairperson: H. Burtt Richardson, Jr., M.D., Winthrop Family Pediatrics Center, Winthrop

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