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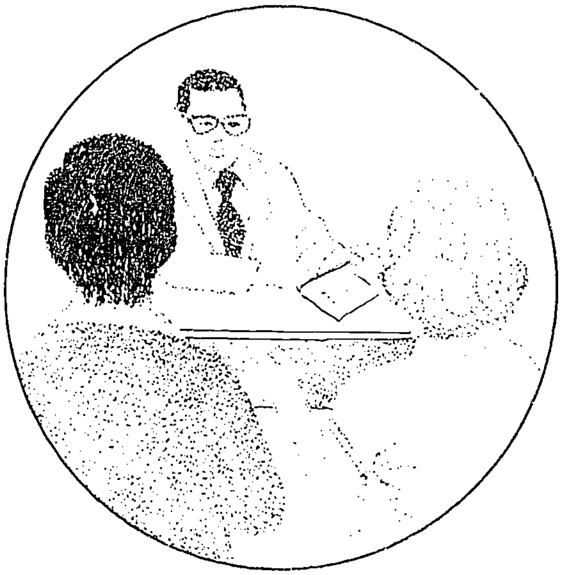
ABSTRACT

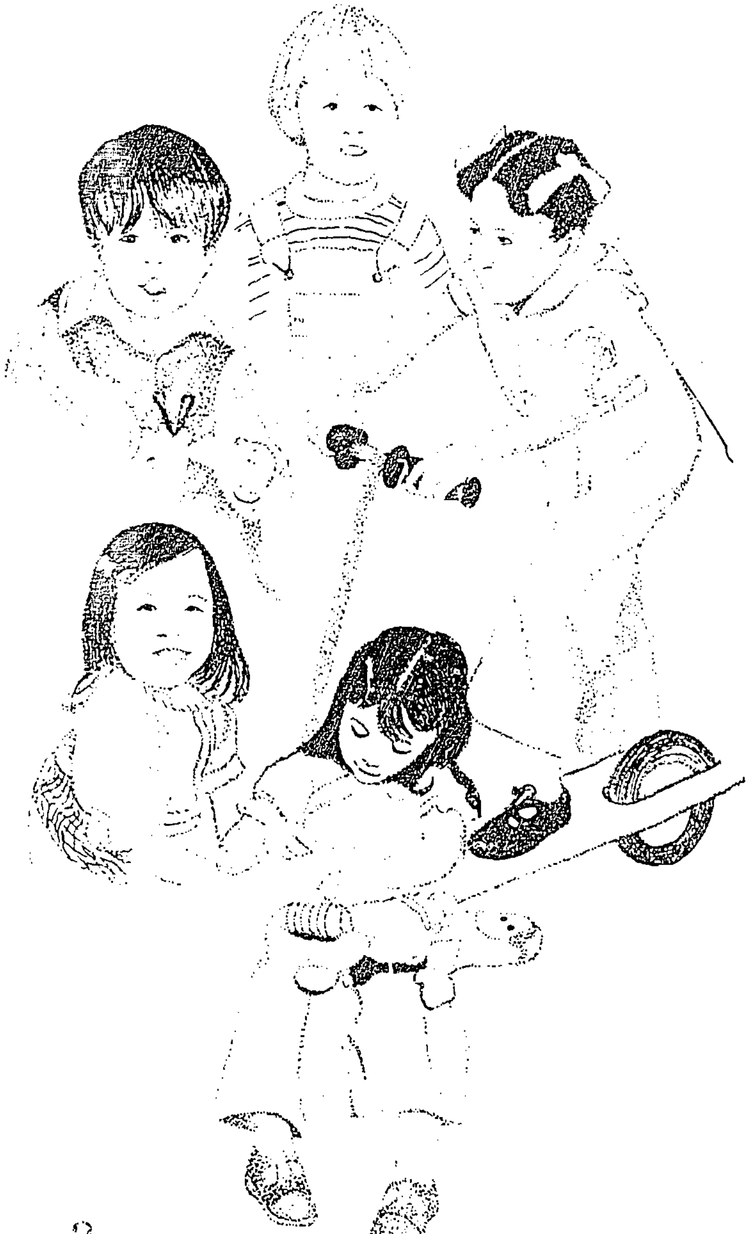
The report by the President's Committee on Mental Retardation reviews the current state of knowledge in the area of biological and environmental prevention of mental retardation and describes programs on the frontiers of research or service delivery. Section I examines programs that are effectively preventing mental retardation through biomedical intervention. Subsections consider genetics (including genetic counseling and screening of newborn infants), perinatal intensive care, and immunization. Programs at Columbia University, Memphis (Tennessee), and the Rose F. Kennedy Center for Mental Retardation and Human Development are noted. Considered in Section II are environmental prevention programs with discussion of preparation for parenthood, programs for mothers and children, mother training programs, infant and toddler stimulation, home teaching programs, Head Start, and elementary school programs. Project Impact, a program to help low income and minority individuals prevent mental retardation and a Taos (New Mexico) program to prevent mental retardation among native Americans are highlighted. Multifactorial conditions such as teenage pregnancy, nutrition, and lead poisoning are the focus of Section 3. Highlighted are two programs at the University of Alabama. Prevention resources are considered in the final major section and include the University Affiliated Facilities' activities in mental retardation research centers, and maternal and child health prevention programs and special initiatives. States with particularly good programs in the areas of prevention, genetic screening, and early casefinding are identified. Also included are the previous recommendations on prevention by the Committee, a summary of the report, and the Committee Resolution on Prevention which advocates a vigorous national prevention effort. (DB)

REPORT TO THE PRESIDENT

MENTAL RETARDATION: PREVENTION STRATEGIES THAT WORK

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION





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PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of Human Development Services
Washington, D.C. 20201

December 3, 1980

The President
The White House
Washington, D. C. 2[illegible]00

Dear Mr. President:

I am pleased to transmit to you the Twelfth Annual Report of the President's Committee on Mental Retardation entitled <u>Mental Retardation: Prevention Strategies That Work</u>.

The Committee points out the fact that mental retardation is America's number one health problem affecting children today. Each year an ever increasing number of mentally retarded babies will be born unless we intensify prevention efforts. One out of every ten persons in this country has a mentally retarded person in the family.

Many cases of mental retardation are preventable. Experts in the field tell us that of the more than 200 known causes of mental retardation -- including injuries at birth, toxic conditions, inherited genetic factors, measles, diabetes, mumps, lead and household poisoning, metabolic disorders, Rh blood diseases, etc. -- more than 50 percent are preventable. Experts have found a significantly larger percentage of mental retardation resulting from environmental influences, including socio-cultural disadvantages, to be preventable.

Recognizing the significance of these findings, the Committee embarked on a study of the distinguishing features of strategies known to be successful in preventing mental retardation, and toured America in search of programs and projects implementing such strategies. Committee conclusions resulting from the intensive study and search are contained in this report.

I hope that this Report will increase public awareness of the preventable causes of mental retardation, and serve as an aid to the promotion of national, state and local activity to reduce the incidence of this serious handicapping condition.

Sincerely yours,

Patricia Roberts Harris

Patricia Roberts Harris
Chairperson

REPORT TO THE PRESIDENT

Mental Retardation: Prevention Strategies that Work

President's Committee On Mental Retardation

Washington, D.C. 20201

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In [illegible] number of cases, mental retardation can be prevented. This report presents a sampling of effective programs from across the country that are part of a national effort to prevent mental retardation and to alleviate its effects. They offer models for others to follow.

Some of the more important bio-medical strategies presented involve newborn metabolic screening and prenatal care, genetic screening and treatment, neonatal care for high-risk infants, and follow-up for these children. In the environmental area, some effective approaches involve Head Start and Home Start programs, family planning, community outreach. Other programs assist teenagers to prevent pregnancy or deal with the unique needs of Native Americans, other minority groups, and rural residents.

These programs were chosen to be only *representative models* of successful strategies, and not necessarily the best program of a particular type.

The development of this report was assisted by Naomi Gray Associates under HEW Contract No. 105-[illegible]—200. An Advisory Group and the Staff of the President's Committee on Mental Retardation provided invaluable assistance in the preparation of this report.

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DEDICATION

The President's Committee on Mental Retardation (PCMR) wishes to dedicate this Annual Report to its long standing Senior Consultant George Tarjan, M.D. with deep appreciation for his many years of untiring effort and support of the PCMR goals and activities.

Through his leadership in the field of mental retardation, Dr. Tarjan has been nationally and internationally acclaimed. As a critical thinker, he has isolated key issued for thoughtful deliberation. He has been a planner and shaper of social policy for more than 30 years: A teacher, a scientist, a clinician and a humanitarian.

In the preparation of this Report, the total dimensions of the role that Dr. Tarjan has played over many years of providing leadership in combating mental retardation have emerged; the elder Statesman, the critical thinker and the problem solver. In this role, his unique quality of bringing together people of diverse backgrounds and points of view; his ability to formulate insightful questions to further spur the group to solution, his ability to recognize and accept his own mistakes, his sensitivity, gentility, humility, levity and wisdom, his ability to work comfortably with all persons—from the most naive to the most sophisticated—was a stimulating and stablizing force behind the preparation of this Report.

His research has added new knowledge above the natural life experiences of mentally retarded persons, and his foresight has permitted more accurate assessment of the future, and therefore better planning.

With his ever present pipe in hand and in his typical patient and tolerant manner, Dr. Tarjan's charisma and leadership make him a cultivator of human resources, inspiring the work of others. All the Committee Members, Consultants, and staff who have had the privilege of working with George Tarjan have come away wiser and better human beings as a result of their experiences with this remarkable man.

ACKNOWLEDGEMENTS

The President's Committee on Mental Retardation wishes to express appreciation to the following contributors to this report:

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For the staff of the programs visited which are highlighted in this report, we express appreciation to:

University of Alabama in Birmingham/
The Medical Center
Center for Developmental and Learning Disorders
Infant Stimulation Program
Teen-Tot Clinic

University of Tennessee, [illegible]
Child Development Center
Center for the Health Sciences

Birmingham, Alabama
The EPIC School (Educational Programs for the Individual Child)

The New Mexico Family Planning Program
Taos, New Mexico

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Juniper Gardens Children's Project, University of Kansas, Kansas City, Kansas

Norfolk Childhood Lead Poisoning Prevention Program Norfolk, Virginia

University of Cincinnati College of Medicine, Department of Pediatrics, Infant Stimulation/Mother Training Project

PREFACE

The Executive Order of May 11, 1966 establishing the President's Committee on Mental Retardation, and the subsequent Executive orders including the most recent one dated December 28, 1978 have all directed the Committee to submit an annual report to the President.

The annual reports have helped the Committee fulfill its mandated function to provide assistance and advice to the President and Secretary of Health and Human Services concerning mental retardation. One specific area of importance emphasized in the most recent (January 18, 1979) Charter of the Committee is the "development and dissemination of such information that will tend to reduce the incidence of retardation and ameliorate its effects."

Consequently, this report entitled "MR 79: Prevention Strategies that Work" is a direct outgrowth of the Committee's activities as specified in the Presidential Order and the Charter. It is also the result of the continuing interest and efforts of numerous Committee members who have been active participants in Committee Task Force Groups focusing on prevention through biological and environmental interventions.

In developing the ideas for this report, Committee members have visited numerous prevention programs throughout the country, have sought advice and information on prevention strategies from various groups within government, in universities and in concerned consumer and professional organizations. Discussions have been held with Prevention Committees, Subcommittees or representatives of the American Association on Mental Deficiency, the American Association of University Affiliated Programs, the National Committee on Children with Handicaps of the American Academy of Pediatrics, and the National Association for Retarded Citizens, Maternal and Child Health of the Bureau of Community Health Services, National Institute of Child Health and Development, Mental Retardation Research Centers, State Coordinating Association and the Office of Special Education.

Therefore, in developing this report on Prevention, a wide spectrum of advice, participation and ideas has been sought and utilized.

The objective of this report is to highlight the current state of knowledge in the area of prevention, whether it is primary prevention aimed at eliminating factors directly producing mental retardation or secondary prevention aimed at modifying or mitigating any adverse circumstances, environments or conditions which may contribute to depriving developing children from realizing their maximum potential. The report, therefore, attempts to determine or define the "state of the art" for biological and enviromental intervention modalities and to provide illustrations of what can be accomplished by describing programs that may be on the frontiers of research or on the "firing line" of service delivery. Examples that are provided are representative of the best, but obviously are not the only such programs available.

Finally, this report, particularly in the Summary, Conclusions and Challenges for the Future Section, highlights and summarizes some of the most important current prevention activities and specifies the most salient directions and goals to be achieved. It is a call to action to apply what we now know, to study further what we must soon learn and, consistent with the Committee's Charter as applied to prevention activities, to identify "the potential of various Federal programs for achieving Presidential goals in mental retardation and coordination of Federal agencies in the mental retardation field." We hope that this report will stimulate major new initiatives in the prevention of mental retardation in our country.

HERBERT J. COHEN, M.D.
Vice-Chairperson
President's Committee on Mental Retardation

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INTRODUCTION

The prevention of mental retardation can be loosely categorized into primary, secondary and tertiary levels of intervention. A conceptual matrix can be elaborated which defines these terms as follows:

Primary prevention represents the attempt to eliminate the occurrence of the problem in the individual and to reduce the prevalence in the community. Classical examples of this include: addressing the medical and social factors, including poverty, which predispose to mental retardation; improving prenatal and perinatal care and factors within these time frames which directly lead to mental retardation; prevention of postnatal causes including catastrophic illnesses, accidents, poisonings, and abuse and neglect which lead to abnormal development.

Secondary prevention attempts to identify a problem early so that intervention at the outset will eliminate the potential for abnormality or alter the circumstances which create the condition. Traditional examples of these include early identification of high risk conditions and early medical, social and educational or other therapeutic interventions.

Tertiary prevention is aimed at minimizing the long term disability or at least mitigating some of its effects. This usually takes the form of case finding and provision of specific and/or comprehensive services for individuals or populations at large.

In viewing the problem of prevention or the distribution of services, it is evident that the predominant population receiving services are those already identified as being mentally retarded whose disabilities are permanent, and for whom improved living conditions or therapeutic approaches are the major mode of service provision and delivery. Next most common are attempts to offer tertiary prevention. Primary and secondary prevention efforts tend to receive less attention. The latter, therefore, will be the major areas emphasized in this report.

In attempting to bring the issues into clearer focus, several specific preventive approaches will be explored. Preventive efforts will be described or portrayed in terms of:

1. The biological/medical primary prevention activities;
2. The social/environmental/educational/habilitative secondary preventive interventions;
3. Circumstances where there is an overlap of primary or secondary, or medical and social-environmental factors, causing disability.

This document, therefore, does not attempt to redefine areas of prevention, but to illustrate, or highlight, in a commodious manner, important examples of prevention efforts and techniques now being employed to make them more effective.

SECTION I: BIOMEDICAL PREVENTION: PROGRAMS THAT WORK

Severe forms of mental retardation, in which the IQ is less than 50, can, in general, be traced to biomedical factors, including genetic defects such as chromosome disorders, metabolic abnormalities or polygenic conditions; intrauterine or extrauterine infections; intrauterine exposure to toxic (teratogenic) compounds; trauma at the time of birth or thereafter; and low birth weight. These types of mental retardation are associated with physical abnormalities such as dwarfism (below normal height), abnormal facial features and cerebral palsy.

According to a report from the Center for Disease Control (CDC) in Atlanta, about 15,000 infants were born with genetic disease and birth defects with associated mental retardation in 1976. About 5,000 of these had anencephaly (almost total failure of development of the brain and the bone that covers it) or spina bifida (an opening along the spinal column often accompanied by exposure of the spinal cord); 5,000 suffered from the results of Rh blood group incompatibility between mother and infant resulting in jaundice and its complications in the newborn period; and 3,000 were born with Down's syndrome. About 600 suffered from congenital hypothyroidism and 200 from PKU (phenylketonuria).

Some genetic disorders, such as Down's syndrome, can be easily identified at birth because of the distinctive appearance of affected infants, including a flattened back of the head, upward slanting eyes and small skin folds at the inner corners of the eyes. Other conditions do not become apparent until later in the first year of life. For example, the baby with Tay-Sachs Disease appears normal at birth, but, after several months of apparently normal development, the infant begins to deteriorate with loss of speech and vision, followed by convulsions, and death prior to the age of five years. This condition, limited for the most part to Jewish people of Eastern European origin, is caused by a single abnormal recessive gene. If parents have had one affected child, their risk of having another affected child with any future pregnancy is one in four. Although no treatment is available for Tay-Sachs Disease, the courses of PKU and congenital hypothyroidism can be significantly altered by early treatment.

PKU, like Tay-Sachs Disease, is caused by a single abnormal recessive gene. It affects approximately one in 15,000 liveborn infants, and is caused by the deficiency of an enzyme. All proteins in the body are made up of amino acids. Phenylalanine is one of those amino acids, and its major source is the diet. It is necessary for normal growth and body functions, but in excessive amounts it causes permanent brain damage. Phenylalanine is normally converted in the body cells to another amino acid, tyrosine, under the influence of an enzyme called phenylalanine hydroxylase and its various "cofactors." In PKU the enzyme or a cofactor is deficient and phenylalanine is accumulated in the developing brain. The accumulation can be prevented by using a diet very low in phenylalanine.

Although there is still discussion about how long the individual with PKU should remain on the diet, most centers recommend discontinuing the diet at three to ten years with the average age being six. However, 14 centers feel the diet should be continued indefinitely. It is also generally considered important to monitor female PKU children as they develop because, even though they may appear to develop normally, a woman born with PKU may continue to have a high phenylalanine level in her blood, and when she is pregnant, her high phenylalanine blood level may result in severely retarded offspring. Thus, such a pregnant woman should be on a special low-phenylalanine diet so the child isn't affected.

Thyroid hormone is necessary for growth, brain development and other body functions. About one in 5,000 babies is born without a thyroid gland. Untreated, the affected infants are destined to be severely mentally retarded and dwarfed. The entire picture can be prevented, if, *in early infancy*, the affected baby is recognized and given thyroid extract by mouth. The two conditions, PKU and congenital hypothyroidism, are examples of devastating conditions whose effects can be prevented by fairly simple therapeutic measures.

Significantly, severe mental retardation occurs regardless of the family's educational level or socio-economic class. Therefore, preventive measures must embrace individuals of all social levels. The parents of children with severe mental retardation are, in most cases, normal. The parents of mildly retarded children are more likely to be mentally retarded themselves, when low income and impoverished social and learning environments are major factors. To be effective, preventive measures must be instituted early.

In the case of maternal rubella (German measles), immunization of all infants at one year of age or later will prevent the occurrence of the disease in the pregnant woman.

Screening of populations of Eastern European Jewish people for the presence of the gene for Tay-Sachs Disease prior to childbearing can identify couples at risk and, thus, can potentially prevent affected children. One such gene carried by a person has no effect; two genes, one inherited from each parent, are necessary for the manifestation of the disease.

Screening of all newborns for PKU and congenital hypothroidism can identify affected infants, thus allowing early treatment and prevention of the mental retardation that is inevitable without treatment.

GENETICS

More than 100 genetically determined biochemical disorders of metabolism have been identified in the unborn baby.

About 100,000-150,000 infants, representing three to five percent of the three million annual births in the U.S.A., are destined to be mentally retarded; some have other accompanying birth defects.

Several strategies are available to prevent mental retardation due to genetic factors, including:

1) genetic counseling for parents or prospective parents known to be at risk for producing a mentally retarded child;
2) screening of newborn infants for selected metabolic diseases;
3) screening of segments of the population to identify individuals and couples at risk for having affected children;
4) prenatal genetic diagnosis to detect abnormalities in the developing fetus;
5) early treatment of affected children, if treatment is available.

Genetic Counseling

In genetic counseling, an appropriately trained professional provides information to individuals or families at risk for genetic disease. This includes information on the nature of the condition for which a risk does or may exist; it features and the outlook for affected individuals relative to life and health. It also involves providing statistics on the risk of occurrence or recurrence of genetic disease in the family; the available treatment of the disease condition; and options for dealing with genetic risk (such as refraining from reproduction, prenatal diagnosis of genetic disease, adoption, artificial insemination, etc.) in a manner in keeping with their family goals and ethical or religious beliefs. Genetic counseling further provides support to individuals and families in adjusting to the conditions and in adjusting to options chosen for dealing with their genetic risks.

Genetic counseling is a necessary part of any overall genetic program involving screening for affected individuals, screening for normal parents who have an increased risk of producing affected children, or prenatal diagnosis of genetic disease. Any person identified in a population screening program must have access to genetic counseling, or else the screening program fails in one of its major preventive responsibilities. The accuracy of genetic counseling depends on an accurate diagnosis of the condition affecting the individual or family and on an accurate assessment of the genetic mechanism which has produced the condition.

Historically, and still, families are referred for or seek genetic counseling primarily because of the existence of a person with a definite or possible genetic condition. In that situation, genetic counseling is provided "after the fact", and one major goal is the prevention of further affected individuals in that family. Population screening programs or screening of relatives of an affected person may allow genetic counseling of couples-at-risk *before* they have any children: counseling "before the fact", such should be a major goal of any genetic prevention program.

Screening of Newborn Infants

PKU, congenital hypothyroidism and several other much rarer conditions that cause mental retardation can be detected in the newborn infant by testing a small specimen of blood, with a follow-up test done later, to verify the findings. Since the late 1960's, screening of newborn infants for PKU has become routine as a means of identifying affected infants so that dietary treatment may be instituted *before* brain damage occurs. In 43 states, screening is required by law, and in other states it is provided voluntarily.

In a few but increasing number of states, the same blood samples are used to test for congenital hypothyroidism and some of the rarer conditions as well. Early identification of the infant with congenital hypothyroidism will lead to early treatment with thyroid hormone—again, *before* the onset of significant brain damage.

While blood specimens obtained for PKU and hypothyroid screening could be used to test for additional metabolic abnormalities, the cost of these tests keeps them from being added since the incidence of most metabolic diseases is so low. Also, not all maternity hospitals and medical centers have the laboratory facilities for accurate analysis, so the samples are frequently sent to a central laboratory for testing.

There are, at present, over 100 regional laboratories including five that handle screening for several States. One of these larger testing centers is in Oregon. It tests blood samples from babies born in Oregon, Idaho, Montana, Nevada, and Alaska. Another one, in Massachusetts, does tests for Connecticut, New Hampshire, Maine, and Rhode Island, as well as Massachusetts. A third network in Colorado does testing for Arizona, New Mexico and Wyoming. Maryland tests blood samples from babies born in Delaware also.

The regional laboratories in Oregon and Massachusetts are the largest. They test for several other genetically caused metabolic disorders besides PKU and hypothyroidism, including galactosemia, homocystinuria, tyrosinemia, maple syrup urine disease, and histidinemia. Although most of the other laboratories test only for PKU and sometimes for hypothyroidism, these other tests could be easily added, since all of them employ methods similar to those used in the PKU test.

The low cost of these screening programs, coupled with their results in identifying children who might otherwise become retarded, make them highly cost-effective. For instance, since each screening costs approximately $2.50, the outcome of 10,000 screening tests can cost up to $25,000. But according to a PCMR 1978 Legislative Proposal, the extra cost of care for a PKU child for life is at least $720,000 -- about 30 times the cost. Then, if the child develops normally and lifetime earnings are added, the cost differential is even more.

Mass screening is the most economical and logical approach when done in a few centralized laboratories, since each condition to be screened for is rare and the testing equipment expensive. Only one child in about 4,000 is born with hypothyroidism, and one in 15,000 or more with PKU and even rarer disorders. To identify a few positive cases, a center should screen at least 25,000 births a year and should be a regional one serving a population of several million.

As mentioned previously, genetic counseling must be made available to the parents of an affected infant identified in any screening program. For parents of a baby with PKU, for example, the risk of an affected baby resulting from any future pregnancy is one in four. Parents must have access to this information.

As new methods for screening are devised, the list of conditions meeting the criteria for screening will be lengthened, thus broadening the spectrum of preventable conditions.

Screening to Identify Individuals and Couples At-risk for Having Affected Children

Genes occur in pairs. Each parent always passes one member of every pair of genes to any offspring. If both unaffected parents carry one normal gene and one abnormal gene, (each then being a heterozygote for the gene), there is one in four probability that each will pass the abnormal gene to an offspring. If that occurs the offspring will have the disease produced by the two abnormal genes.

The objective of heterozygote screening programs is to identify those normal individuals and couples who carry one dose of an abnormal gene so that they can be provided genetic counseling *before* they have any children. To do so, a test must be available that specifically and accurately identifies the heterozygotes, and must be economically feasible. Practically speaking, economic feasibility also depends on the identification of a population in which the heterozygote is very frequent.

A prime example of such a condition is Tay-Sachs Disease, mentioned earlier in this report. Approximately one in 3,600 babies in Eastern European Jewish populations has Tay-Sachs Disease, while only one in 360,000 non-Jewish babies is affected. Approximately one in 30 healthy persons in those same Jewish populations is a heterozygote for the gene that causes Tay-Sachs Disease. Thus, for Tay-Sachs Disease we have a population in which the frequency of the abnormal gene is quite high.

Tay-Sachs Disease, like PKU, is caused by the deficiency of an enzyme. The missing enzyme in Tay-Sachs Disease is called hexosaminidase-A. The blood of affected babies contains very little of the enzyme. Even the blood of healthy heterozygotes for the Tay-Sachs genes contains less hexosaminidase-A than that of people who do not carry the gene. Consequently, heterozygotes can be identified by a simple, inexpensive blood test, that can be applied to large numbers of blood specimens.

If both members of a couple are tested before they have children, and both are found to be heterozygotes for the Tay-Sachs gene, they can be provided genetic counseling, and can be offered options for pregnancy at a later time, including prenatal diagnosis for preventing the birth of an affected child.

For heterozygote screening programs to be applicable, the target condition must be fairly frequent in the target population, and options for dealing with the attendant risk (for prevention of affected offspring) should be available. While newborn screening programs for the identification of infants affected with genetic disease can be defended on a mandated, population-wide basis, heterozygote screening programs should be voluntary, and should always be accompanied by a program of education of the target population relative to the implication of the disease tested for, and to the genetic risks involved. Results must be made available to all persons and couples tested, but must be kept confidential. The availability of screening to a person or couple should never be predicated on a commitment by the couple or person to take any specific action on the basis of results provided to them.

A second type of screening is on the horizon for normal parents who have a risk of producing abnormal offspring. About one in 1,000 or more babies born in the U.S.A. have an open spine defect (also called a neural tube defect). If the opening involves the head and brain, it is called anencephaly or encephalocele; if it involves the spine below the head it is termed a meningocele or meningomyelocele. All babies with anencephaly are stillborn or die in the first few days of life. Babies with the other forms of open spine defect may survive, but a significant portion have permanent paralysis of the legs and may have associated mental retardation. The blood of a pregnant woman whose unborn baby has an open spine defect contains excessive amounts of a protein called alpha fetoprotein (AFP). Pilot programs have been conducted in the U.S.A. on the feasibility of widescale testing of AFP in the blood of pregnant women. While the test is not specific for open spine defects, it does identify those women whose unborn babies may be affected. They can then be offered more specific testing, including amniocentesis and ultrasonography. Within the near future, this test will be available nationwide and has the outlook of being very reliable in the prevention of one major cause of mental retardation.

Like newborn screening, screening of normal parents at risk for producing mentally retarded offspring will encompass an ever widening spectrum of conditions as new technologies are developed.

Genetic Diagnosis to Detect Fetal Abnormalities

Prenatal genetic diagnosis encompasses a number of procedures designed to assess the condition of the unborn baby. They include ultrasonography, radiography, and amniocentesis. Test results provide information to parents, relative to a selected group of conditions, on whether their unborn baby will have the condition tested for. It is offered for two reasons: first, if the unborn baby is found *not* to have the condition for which the test is done, they can be reassured; secondly, if the unborn baby is found to be affected, the parents can be offered the opportunity to terminate the pregnancy.

Occasionally, third and fourth reasons apply: even if parents do not opt to terminate the pregnancy if their unborn baby is found to be abnormal, they may wish to have prenatal diagnosis to prepare them for the birth of an abnormal infant. In a few conditions, prenatal diagnosis of a treatable condition will allow institution of treatment immediately after birth with no delay in diagnosis

Transabdominal amniocentesis is the most widely used method of prenatal diagnosis. The unborn baby is surrounded in the uterus (womb) by a fluid called amniotic fluid. The fluid contains chemical compounds originating in the unborn baby, plus cells derived from the unborn baby. Measurement of chemicals in the fluid can lead to the detection of some abnormal conditions. The cells contained in the fluid can be stimulated to grow in the laboratory, and on those cultured cells chemical tests and chromosome studies can be performed.

The most frequent and best known chromosome abnormality that produces mental retardation is trisomy for chromosome 21, resulting in Down's syndrome. Potentially, any chromosome abnormality can be detected in the unborn baby through a study of amniotic cells.

A number of metabolic diseases that produce mental retardation are also reflected in chemical assays performed on cultured amniotic cells, including Tay-Sachs Disease. In addition, the increased concentration of AFP in the aminiotic fluid itself may indicate an abnormal baby, including the presence of an open spinal defect. The number of genetic disease detectable in the unborn baby is likely to increase significantly in the near future because of the development of new techniques that are "spin-offs" of DNA research.

Amniocentesis is ordinarily performed in the 14th to 16th week of pregnancy, measured from the first day of the mother's last menstrual period. It is widely accepted because of its high level of accuracy in diagnosis—more than 99 percent—and its low procedural risk—only about 0.5 percent at most. The procedure involves the insertion of a thin hollow needle through the wall of the mother's abdomen, through the wall of the uterus, into the sac containing the unborn baby and its surrounding amniotic fluid. Approximately one ounce of fluid is withdrawn into a plastic syringe. Using the fluid, biochemical tests can be performed, uncultured cells can be tested for some conditions, and cells can be placed in culture for chromosome studies and other biochemical tests.

Since the procedure does have some small risk, specifically for the unborn baby, the prospective patient is always counseled about the risks and the limitations of the procedure before it is done. Studies conducted in the U.S.A., Canada, and Britain have not differed significantly relative to risk. The risk of importance involves miscarriage (spontaneous abortion) following the procedure. As noted above, that risk is in the range of 0.5 percent.

Amniocentesis should always be preceded by an ultrasonogram. This technique involves the passage of ultrasonic waves through the abdomen of the pregnant woman and their detection by a sensor on the abdominal wall. It appears to be harmless, and provides an image of the uterus and its contents, the unborn baby and the placenta. An ultrasonogram is done prior to amniocentesis in order to determine whether the uterus contains one or more than one fetus, to determine the stage of pregnancy (how many weeks), to determine the position of the placenta so the obstetrician can avoid the placenta in performing the amniocentesis, to be certain the fetus is alive, and to detect certain birth defects. Ultrasonography may detect such abnormalities as a small or large head, an open spinal defect, or others. Thus ultrasonography has a role in detecting certain abnormalities itself in addition to its role in preceding amniocentesis.

The skeleton of the unborn baby is visible by radiography (x-ray) by about 20 weeks gestation and may be used to detect certain conditions associated with bone abnormalities. Certain x-ray contrast materials may be injected into the amniotic fluid to outline the newborn baby in an effort to detect some abnormalities.

The following situations have been widely employed as indications for offering prenatal diagnostic procedures to women at risk for having abnormal babies:

1) **The woman who has a baby when she is 35 years of age or older.** It has been shown conclusively that, as women become older, their risk of having babies with certain chromosome abnormalities increases. For example, for women under 30, the chance of having a baby with Down's syndrome is less than one in 1,000. By age 35, the risk has increased to slightly over one in 400. At age 40 the risk is approximately one in 100; by 45 it is about one in 32, and at age 50 it approaches one in ten. Because of this maternal-age related risk, it is the practice in most centers for women who will bear a baby at age 35 or older to be offered amniocentesis. Advanced maternal age is the reason for over 75 percent of all amniocenteses.
2) **The previous birth of a baby with a chromosome abnormality.** A woman who has had a baby with a chromosome abnormality may be at increased risk for having another baby with a chromosome abnormality. For example, even at a young age, if a woman has had a baby with Down's syndrome, her risk of a second affected baby approaches one percent.
3) **A chromosome abnormality in a parent.** Some chromosome abnormalities, termed balanced translocations, produce no abnormality in the people who have them. However, those carriers of translocations have a risk of producing abnormal, mentally retarded offspring significantly greater than the general population. Such a carrier may have a 15 percent or greater risk of producing an abnormal offspring.
4) **Couples in which both members have been shown to be heterozygotes for the same recessive abnormal gene.** Such couples have a risk of one in four of producing an affected offspring with each pregnancy. If a test is available for the disease in question, those couples should be offered amniocentesis.
5) **A woman who has previously had a baby with an open spine defect.** About one in 1,000 babies born has such a defect. A mother who has previously had an affected baby has a risk of about two percent of having another affected infant with any future pregnancy. In addition, a few women have survived an open spine defect themselves and are able to have children. Their risk for an affected infant is also in the two to three percent range. While not a specific test for open spine defect, an increased concentration of AFP in the amniotic fluid may signify the presence of an open spine defect in the unborn baby. It appears that another compound called acetylcholinesterase, if present in the amniotic fluid in abnormally high concentration, is much more specific for open spinal defects, and can be used to confirm an elevated AFP concentration. Any woman who has had a previous baby with an open spinal defect or who, herself, has had an open spinal defect, should be made aware of the availability of amniocentesis. Ultrasonography may also be helpful in detecting an open spinal defect.
6) **A woman known to be a heterozygote for an abnormal gene located in the X chromosome.** Such abnormal genes produce disease only in males (examples are hemophilia and Duchenne muscular dystropy) but are transmitted by unaffected heterozygous mothers. Most such conditions are not diagnosable prenatally, but the pregnant woman may request an amniocentesis to determine the sex of the unborn baby. If the baby is a female, she cannot be affected; if a male, he has a one in two chance of being affected.

Other less clear-cut indications for prenatal diagnostic procedures are a family history of chromosome abnormalities (other than a previous affected child); a previous child with multiple birth defects of unknown cause; and a history of multiple miscarriages.

While the detection of an abnormal baby by prenatal diagnosis may lead to a therapeutic abortion, recent evidence indicates that there are fewer such pregnancy terminations now than there were before prenatal diagnosis became available.

Previously, pregnant women at risk for affected offspring sought a therapeutic abortion simply on the basis of their risk and without informed knowledge.

Only about two to three percent of prenatal diagnostic procedures produce abnormal results. While by no means the ultimate answer to the prevention of mental retardation, prenatal diagnosis provides parents an option not previously possible.

PERINATAL INTENSIVE CARE

Perinatal intensive care is an important factor in the prevention of retardation, as well as in the reduction of the perinatal infant mortality rate. It has been used most particularly for the low birth-weight premature infant, who is generally unable to survive without such care.

The survival rate for these infants has increased dramatically in the last decade, as reported by Children's Hospital Medical Center in Washington, D.C. Prior to 1970, the majority of babies under 3½ pounds died. But now the majority survive down to 2½ pounds. Even the survival rates for babies under 2½ pounds have been improved. Until about 1975, the survival of these babies was rare, but now up to 60 percent of the infants from 1½ to 2½ pounds survive in some nurseries. The survival rates are highest in hospitals that have referral systems to place high-risk newborns in immediate intensive care. In hospitals without such facilities, the rate is much lower.

Such improvements in newborn infant care have not only increased survival chances, but they have also contributed to an increase in the health and IQ of those infants that do survive. This increase is important, since low birth-weight and premature infants are at a high risk for becoming mentally retarded, due to birth complications, lowered resistance to infections, lack of fully developed nervous systems, and other factors.

In six studies from the 1950's and 1960's, 30-40 percent of the newborns who are under 3½ pounds at birth had developmental quotients (DQ's) of less than 90 at one year, and about 1/3 had severe central nervous system defects, including cerebral palsy. However, now these problems affect only about five to ten percent of low birth-weight newborns.

At the same time, there are still major risks of being handicapped for the low birth-weight baby, particularly if it is also premature. For example, babies under 5½ pounds are about ten times as likely to develop mental retardation as those over this weight. Also, intraventricular hemorrhage frequently occurs in low birth-weight premature babies, and many of these small prematures develop cerebral palsy, often associated with mental retardation.

Thus, while the new technology has contributed to helping premature and low birth-weight infants survive, still further development is necessary and the long-term impact of this new technology still needs to be determined through further follow-up. This long-term approach is necessary, since at one or two years the mean DQ or IQ of the surviving prematures can appear normal. However, at school age, some of those premature infants who have been followed have perceptual defects, learning difficulties and behavioral problems. Thus, better early indicators are needed to identify infants who will subsequently become handicapped.

These data suggest that the intensive care given low birth-weight infants has been successful in not only helping them survive, but also in helping most of them survive as normal, healthy babies.

Columbia University: Coordinating Perinatal Services Through a Perinatal Network

One of the major problems in American medicine is a lack of organized medical care, leading to the maldistribution of resources and available services. In the perinatal field, major technical advances have made medical personnel increasingly aware of the need for organized planning, since this advanced technology (such as electronic fetal and maternal monitors, and genetic testing) can be used to give low birth-weight and otherwise at-risk infants an increased chance of survival.

But many infants do not have access to it, since traditionally hospitals have operated independently, and obstetrical and neonatal services have been set up without regional planning. The result has been that while some hospitals have adequate neonatal services, others do not. In turn, the infants born where services are lacking have not had good access to intensive care services when needed, since the coordination with nearby intensive care units has been haphazard.

To help resolve this problem, the Robert Wood Johnson Foundation funded eight regional centers to develop and offer model programs showing the value of regionalization in improving health care, reducing costs, and lowering the perinatal mortality and morbidity rates. One of these centers is in the Western and Upper Manhattan Regional Perinatal Network, administered by the College of Physicians and Surgeons of Columbia University. Membership in the Network is open to all hospitals in the region delivering obstetrical and newborn care.

At the beginning of the program, seven hospitals in Manhattan joined the Network—Presbyterian, Harlem, St. Luke's, Roosevelt, Syndenham, French-Polyclinic, and Jewish Memorial. In 1979, as testimony to the program's success, two more hospitals outside the region joined: Good Samaritan in Suffern, New York, and Stamford Hospital in Stamford, Connecticut. Four other hospitals in New Jersey have also asked to join. Approximately 20,500 delivers are handled by the network hospitals annually.

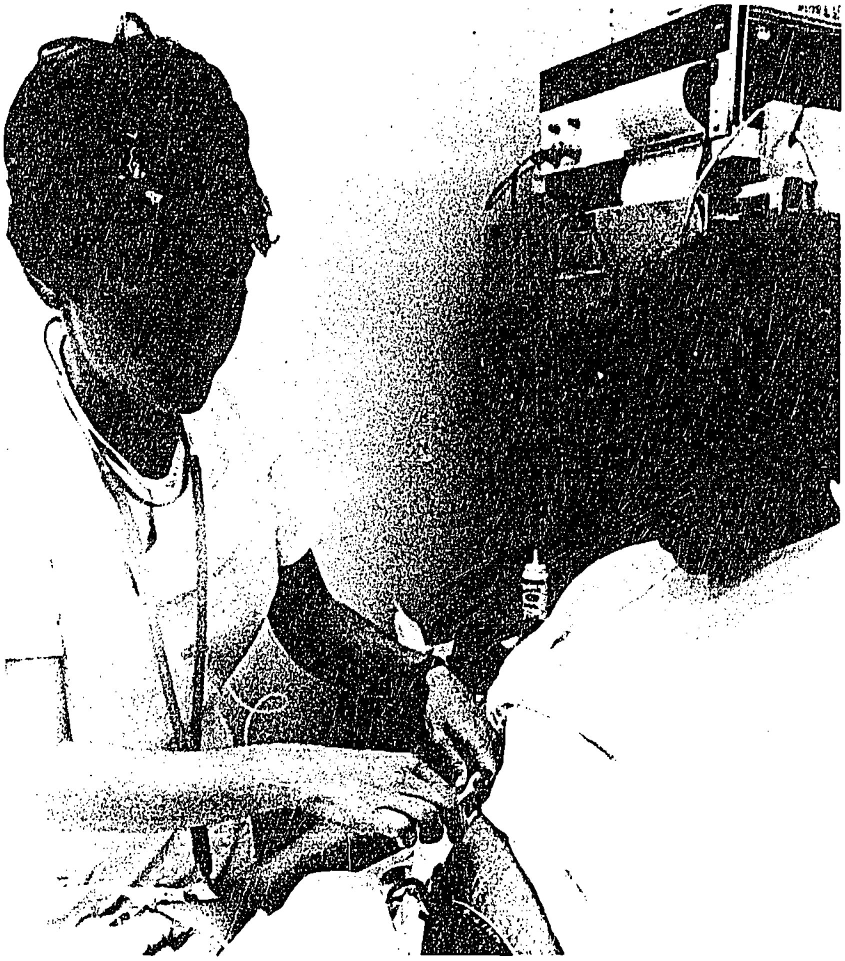
A key feature of the program is that any affiliated hospital can send its premature and critically ill newborns to the neonatal intensive care unit at Presbyterian Hospital for evaluation and treatment. In addition, doctors in community hospitals can transfer their patients to Presbyterian and deliver them there—an important benefit for doctors in smaller hospitals with less technological support. Overall, about 150 newborns have been transported each year and about 150 mothers have been transferred prior to delivery.

Some other major features of the program include the following:

1) A regional perinatal conference is held each month with perinatologists, neonatologists, and other health professionals from all participating hospitals. This

Rick Sheridan

Neonatal transport to Presbyterian Hospital.



Rick Sheridan

Fetal-maternal monitoring in Presbyterian Hospital Labor Room.

conference helps hospitals in the network establish standard practices and review current activities. Also, it is a forum for presenting regional statistics and discussing cases and clinical issues.

2) A common record system has been developed for all hospitals in the Network. Importantly, this system keeps track of data on all births, which are recorded, and entered into a computerized data file for easy access and analysis.
3) Combined efforts have been effective in changing the policies of other agencies when these policies have been detrimental to providing care. For example, Network members were able to persuade the New York State Department of Social Services to abandon its "four-month rule" requiring patients to be four months pregnant before applying for Medicaid. Because of the two months needed to process these applications, this rule prevented pregnant women from getting prenatal care until the third trimester. Now, financially eligible patients can apply once their pregnancy is medically verified.
4) Network efforts have been effective in sensitizing government officials about the importance of prenatal care and the need to remove financial barriers to such care. For instance, the Network referred to the Governor of New York a report it prepared on the problems of unregistered obstetrical patients who did not receive prenatal care because of financial need and suffered more complications in pregnancy. As a result of this report, the Governor has made the provision of prenatal care a priority item in his health message. Also, several Network staff assisted in drafting preliminary legislation on this issue.
5) The Network has developed outreach activities to inform relevant community agencies and targeted high-risk populations abut its programs. For example, the Network's Community Liaison Committee, composed of representatives from various hospitals, has advised community agencies and leaders about Network activities. Other staff members have given perinatal care lectures in Harlem to encourage the high-risk Black population there to seek care. Still others have distributed pregnancy testing kits to Harlem Hospital, where the perinatal and neonatal death rates have been especially high. Also, the Network developed a brochure for teenagers on where to go for pregnancy tests, family planning, prenatal care, health education, and counseling, and it prepared a guide to maternal health services to help Network health professionals and New York City Health Department outreach workers in advising prospective mothers.
6) The Network established a hotline phone number to refer patients with pregnancy-related problems to appropriate services, and thousands of callers have used the number.
7) Also, the Network has engaged in extensive educational activities. These include:
   - Active nursing education program of full-day workshops and short courses offering the latest information on neonatal and perinatal techniques.

- An inservice educational program for Health Department outreach workers with information on perinatal casefinding, referral, follow-up and current labor and delivery practices to help them locate and assist pregnant women.

8) Finally, the Network has engaged in important research and evaluation efforts. These include:
    - An investigation of the costs of regionalization, and a cost analysis of charges for the services offered by Presbyterian Hospital's neonatal care unit. This cost analysis has involved determining the charges for both routine and ancillary services, including room and board, x-rays, and laboratory tests.
    - Review of the data from the uniform records to evalute the Network's success in cutting down the rates of stillbirths and neonatal deaths.
    - The preparation of a report on nonregistered obstetrical patients in four Network hospitals. This report revealed some important characteristics about these patients, such as a much higher incidence of complications in pregnancy and a higher perinatal morbidity rate compared to registered patients. It also indicated that their major reason for not receiving prenatal care was having no money or no insurance.

Since the Network is only in its fourth year, the results are still being evaluated. However, the program is clearly successful: neonatal and perinatal death rates have dropped significantly in the region since the program began. For example, the neonatal death rate dropped from 17.5 per 1,000 in 1976 to 11.5 in 1978, while the perinatal death rate dropped from 24 to 19 per 1,000 in this same period.

This significan[illegible] occurred because the regio[illegible] approach has allo[illegible] mothers and infa[illegible] better access to intensive [illegible] and neonatal care faci[illegible] this improved care has [illegible] the infants' chances f[illegible]al. The data show that better technology had this effect, since the neonatal and perinatal death rates for babies under 1,000 grams were much lower at Presbyterian Hospital, which has the intensive care unit, compared to other hospitals in the region. At Presbyterian, the neonatal death rate was only 585 per 1,000 compared to 600-750 in other hospitals, and the perinatal death rate only 630 per 1,000 compared to 714-900 elsewhere.

Memphis: Preventing Mental Retardation Through a Comprehensive Program of Genetic Counseling and Screening

The Comprehensive Genetics Program at the University of Tennessee Center for the Health Sciences in Memphis, with its emphasis on genetic counseling and screening, is committed to a broad range of education in genetics, and its research program is designed to make a significant impact on the prevention of genetically caused mental retardation.

The Genetics Program has been funded since 1964 through multiple sources, including the University of Tennessee's education and research funds, a grant from the Maternal and Child Health Division of the U.S. Department of Health and Human Services, a contract from the Department of Public Health of the State of Tennessee (in relation to a statewide genetic program funded by the National Genetic Disease Act), grants and contracts from the National Institutes of Health, a grant from the State of Tennessee Department of Mental Health, grants from the National Foundation March of Dimes, and from the National Council of Jewish Women. The comprehensive program involves physicians, medical geneticists, laboratory scientists, social workers, researchers and technologists.

Working as a team, these staff members provide comprehensive genetic services to individuals with genetic or possible genetic disease and to individuals and couples at-risk for producing offspring with genetically determined abnormalities who live in an eight-State area representing a population of about

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six million. The majority of persons served come from Tennessee and parts of Arkansas and Mississippi, with smaller numbers from Kentucky, Missouri, Illinois, Louisiana and Alabama. Patients have come from as far away as Spain, Puerto Rico, and Venezuela.

The program is located in a University Affiliated Facility (UAF). It provides a full range of clinical and laboratory services that include genetic diagnosis, counseling, screening, intervention and management, and also includes a training component in which medical and dental students, physicians and dentists in graduate training, and other health care professionals learn medical genetics. Staff members engage in extensive educational efforts through seminars and symposia in Tennessee and other States, to acquaint health care personnel with the program so that they will be able to recognize genetic disease and genetic risks.

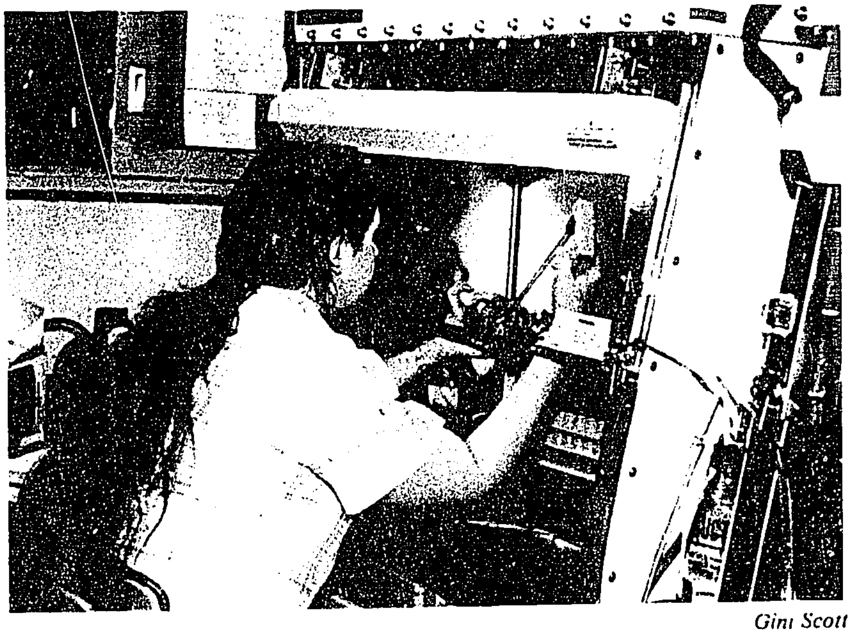
In addition, a research component is designed to advance basic knowledge of genetic disease leading to mental retardation, and to develop new applied cytogenetic and biochemical technologies to improve diagnosis and management of genetic disease. For example, one study conducted by the Genetics Program found that of 500 unclassified mentally retarded children with congenital abnormalities, six percent had a causative chromosome abnormality, compared with less that one percent in normal controls. Other studies have clarified the causative relationship between certain chromosome abnormalities and mental retardation syndromes.

In related metabolic screening programs, staff test urine and blood samples of children with mental retardation in search of abnormal metabolites. Diseases identifiable by these means include PKU and Tay-Sachs Disease, as well as others.

In the genetics clinic, couples at-risk for producing children with genetic disease are referred for counseling. In 1979, genetic services were provided to 777 new families. Among them were 296 couples in which the wife underwent amniocentesis. Most of the amniocenteses were done because of advanced maternal age. Chromosome studies were done on 947 individuals.

In addition to the services described, the program at Tennessee provides follow-up evaluation for all newborns who have been found in the statewide screening program to have PKU. As a State reference laboratory, the biochemical genetics laboratory of the program determines if a newborn discovered by the screening program actually has PKU (the initial test may give false positve results). If so, dietary treatment is instituted and monitored to prevent mental retardation.

The program's comprehensive team approach in cooperation with nutritionists, psychologists, social workers, nurses and pediatricians of the Child Developement Center (UAF) is a key factor in its



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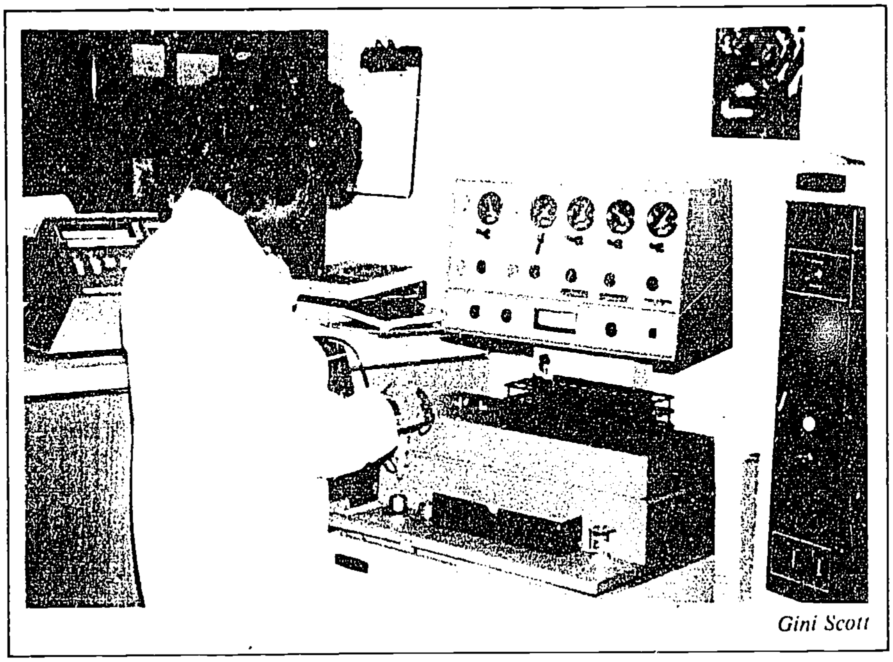

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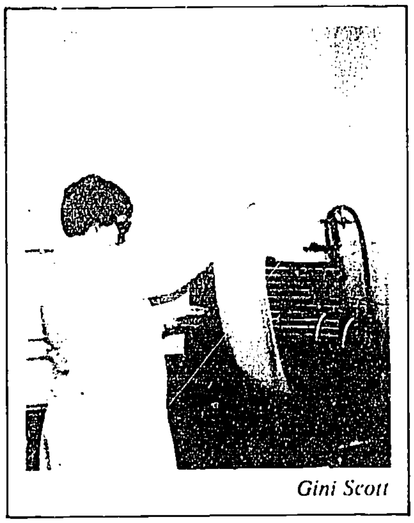

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success, as are its research and education programs on the causes of mental retardation and strategies to prevent it. In addition, members of the staff of the program work with the news media and community groups to inform community members about its screening programs and to encourage their participation. An example is a program carried out in 1976 in which the Genetics Unit launched a campaign, at the request and with the support of leaders in the Jewish community of Memphis, to enlist Jewish people in Memphis to participate in a city-wide screening program to identify carriers of the gene for Tay-Sachs Disease.

Another key factor in the success of the Genetics Program is its affiliation with an early intervention program at the University's Child Development Center, a UAF. When an infant with a genetic disease such as Down's syndrome is identified, the infant is referred to the program for early and concentrated stimulation. The program is open to infants and children up to three years of age. Parents bring them to the Center for one-half day each week for motor and sensory stimulation, social activities and early language instruction. In addition, parents learn how to stimulate their children at home.

Research conducted by staff at the Center has shown this stimulation approach to be extremely effective. For example, when researchers compared 40 Down's syndrome children in the program to 40 non-participants with the same syndrome, they found that the infants who started in the program before six months showed a much greater rate of development. Subsequently, a follow-up study of 20 of the children, three to six years of age, revealed that 65 percent of the children who had been in the program tested at the borderline or mild level of retardation, compared to only 24 percent of the children who had not participated.

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The Rose F. Kennedy Center for Mental Retardation and Human Development: Research, Evaluation and Helping the Low Birth-weight Infant Through the "LIFE" Program

The premature, low birth-weight baby has about a 15 times higher risk of retardation than the normal infant born at term with a normal weight. They are also more likely to have language disorders and other forms of cognitive dysfunction.

At the Rose F. Kennedy Center, located at the Albert Einstein College of Medicine, Bronx, New York, several new programs are designed to deal with this type of infant. Collectively, they are called the "LIFE Program," which stands for "Low Birth-weight Infant Follow-up and Evaluation Program". Under this umbrella are two major research and assessment programs: (1) a program to evaluate the effects of brain damage in the low birth-weight baby on his subsequent development and (2) an infant follow-up and early intervention program to help parents of a low birth-weight baby to understand and cope with their child.

The research program uses two approaches to assess brain functioning and damage, if any. First, a unique integrated battery of morphological, neurobehavioral, and electrophysiological techniques are used to assess brain functioning to detect brain damage in the high-risk infant weighing less than 1,500 grams at birth, and to identify biological causes of this damage. Then the researchers examine the

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consequences of this abnormality for subsequent neurological and behavioral development, particularly in vision and hearing.

A key research goal is to enable medical personnel to define the newborn's brain status accurately and to provide an accurate prognosis for its development. Also, the research is designed to assist medical personnel in providing early intervention to correct specific neurobehavioral disorders.

Since the start of the project in 1979, 112 infants under 1,500 grams have been admitted as patients, and 51 are still being followed longitudinally. The other infants have dropped out due to various factors, the majority (46) as a result of death in this very high-risk population.

Infants are carefully observed while in the hospital. Each day the nursing staff takes a daily medical profile of all clinical and biochemical events, and each week they do a neurobehavioral assessment, using the newly developed Einstein Neurobehavioral Assessment Scale (ENBAS). Also, they measure the infant's head circumference and weight. Then, when the infant reaches an age of 40 weeks post conception, he participates in a full testing program. This includes the usual medical assessment, head and weight measurements, and ENBAS test, plus an electrophysiological assessment to determine potential in vision, hearing the motor-touch behavior.

Later, in the first and second years of life, there are additional tests, including a physical-neurological exam, an electroencephalogram, a visual scanning test, the Bayley Infant Scale Test, language evaluation, and visual and auditory tests.

The preliminary results of this research study are now being assessed and are expected to provide important information on the relationship between brain development and subsequent behavior in the low birth-weight baby.

The other research program to assess the low birth-weight newborn's level of brain functioning involves the Einstein Neonatal Neurobehavioral Assessment Scale (ENNS). A key rationale for this program is that if infants with nervous system disorders can be identified in the newborn period, their potential for development can be evaluated and they can be treated accordingly.

To achieve these goals the ENNS test is given to the infants each week from birth to 40 weeks of age to obtain sequential data on their neurobehavior functioning and sensory abilities, as compared to normal full-term infants. This comparison is made by looking at how both types of infants perform on 24 different measures testing their reaction to different kinds of stimuli, such as being lifted, stroked, hearing noises, and seeing objects. In this way, the infant's response level can be determined for a variety of responses, including sucking, visual following, auditory orienting, blinking, grasping, traction, withdrawal from painful stimuli, rotation, movement and other areas. In addition, the test rates the child's

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general cuddliness, spontaneous movements, temperament, and muscle tone.

The researchers are particularly interested in exploring major deficiencies in visual and auditory responsiveness, since such deficiences occur in almost all low birth-weight babies.

A major study using this technique has been conducted by Diane Kurtzberg and other Center researchers, using low birth-weight and normal infants born between June 1975 and July 1976 at the Abraham Jacobi Hospital of the Bronx Municipal Hospital Center. The researchers selected 118 low birth-weight infants (49 males and 69 females) from the neonatal Intensive Care Unit who weighed less than 2,250 grams at birth, and compared them with 76 normal full-term infants (39 males and 37 females) who weighed 3,580 grams or more.

The differences were striking. The most dramatic were in visual and auditory behavior, where the low birth-weight babies showed markedly less visual and auditory responsiveness than full-term infants.

Also, the researchers found that compared to full-term babies, the low birth-weight infants showed less ability in traction, head extension, responses, rooting, sucking, and grasping. Over 20 percent of the low birth-weight infants had poorer muscle tone. They were also less likely to cuddle or spontaneously cling to the tester, and were much more likely to cry.

Even so, the researcher found much variation among individual low birth-weight infants, and are still assessing the impact of different variables on subsequent development. For example, they believe the identification of a deviant neurobehavioral performance can be used to assign a deviant infant for a more detailed neurological and developmental evaluation. The program is unique in being the first to use this approach.

The other major element of the LIFE program involves early intervention with high-risk low birth-weight infants to achieve three main goals: making parents more aware that a low birth-weight baby is different; helping parents understand and cope with any abnormal neurobehavioral development, and encouraging parents to participate actively in intervention efforts to help their child develop.

At a weekly parent's group meeting, parents discuss current problems and concerns. In addition, nurses from the center make five home visits in the first year of the child's life to evaluate the number and quality of parent-child interactions in the home, and encourage more of them. Also, participating parents bring their children to the center each month for a well baby check-up which involves a complete physical, neurological, and electrophysiological evaluation. The staff uses these tests results to help determine intervention strategies.

When low birth-weight children develop abnormally, the Rose F. Kennedy Center has, through its Children's Evaluation and Rehabilitation Clinic, a large diagnostic and treatment center serving 4,600 children annually. The clinic uses a multidisciplinary team approach to provide aid in all areas of child development—language, cognition, motor, and social activity—to four categories of children: 1) infants or toddlers with developmental problems, 2) school-age children with these problems, 3) children with cognitive disorders; and 4) children who are physically handicapped. Each team includes at least one pediatrician, psychologist, social worker, speech pathologist, and other medical specialists or special educators where appropriate.

IMMUNIZATION

An important aspect in the prevention of mental retardation is the prevention of infections and immunologic reactions that may result in retardation. According to the Director of the Bureau of Biologics in the Food and Drug Administration, several thousand infants were prevented from developing brain damage due to protection provided by three forms of immunization: immunization of future mothers against rubella (German measles); the administration of Rh immune globulin to Rh negative mothers with Rh positive husbands who have had an Rh positive baby; and immunization of infants against measles. Immunization of children against measles and rubella confers long-term protection against the viruses that produce these infections. Blood incompatibilities (especially those involving the Rh blood factor) between mother and unborn infant may lead to severe mental retardation unless the infant's blood is exchanged completely with matching blood from another person. In most cases, the first baby of an Rh negative mother who has an Rh positive husband has no problem. That pregnancy, if the baby is Rh positive,"sensitizes" the mother so that she produces damaging antibodies against future Rh positive babies. That sensitization can be prevented if, immediately following the birth of her first (and any subsequent) Rh positive baby, she is given Rh immune globulin.

Immunization prevents mental retardation in an offspring by protecting the mother against the disease condition that would produce retardation in that offspring. Retardation in her offspring would occur as follows: The mother is exposed to the organism (rubella virus for example) during her pregnancy and, after exposure, develops the infection. During the infection, even if it is so mild that it is not recognized, the virus may travel through the mother's bloodstream to the placenta, where it settles. Then, as it multiplies, it spreads through the unborn infant's blood where it creates a chronic, persistent infection that interferes with the development of or causes direct damage in key organs such as the brain, eye and heart. Congenital defects result from this infection, and in about half of the cases mental retardation occurs.

By contrast, if the mother is protected by having been immunized *prior to her pregnancy* with live virus vaccine (rubella for example,), infection will not develop during pregnancy. The live virus vaccine, if given in childhood for example, does not produce recognizable infection but does result in the production of antibodies that prevent future infection. A woman should *not* be immunized when she is pregnant, since the virus in the vaccine,even though it has been "attenuated," could possibly infect the unborn baby and produce problems.

The effectiveness of immunization programs against rubella has been demonstrated emphatically by the fact that no major outbreak of rubella has occurred in the 15 years since such programs were widely employed following the 1963-64 outbreak of rubella.

Similarly, Rh immune globulin has proved to be nearly 100 percent effective in preventing Rh disease-damage babies in Rh negative women who received it following the birth of prior Rh positive babies. Measles vaccine has likewise been effective in preventing measles, an infection that, in young children, may result in brain damage and permanent mental retardation.

The major problem has been the fact that, even in this age of enlightenment, many children are not immunized against rubella or measles. Parents simply have not realized the importance of having their children immunized, and immunization programs have not been as aggressive as they should have been. A significant proportion of school-aged children have not been vaccinated, and increasing numbers of women and girls entering their childbearing years have never been immunized against rubella.

Vaccines against other infections are under development that may have a major impact in preventing retardation due to bacterial infections that affect the infant and young child. Perhaps the most serious such infection is meningitis, a major source of brain damage, which is caused by three major types of bacteria; Group B streptococcus, E. coli, and H. influenza type B. About one in 1,500 newborn infants, or about 2,000 infants each year, develop meningitis due to bacteria, while about 10,000-12,000 older infants and children are affected. In the case of newborn infants, 25-50 percent die, while most of those who survive are left with permanent brain damage. Among older infants and children, about 50 percent are permanently damaged. However, vaccines preventing infection by these forms of bacteria will be available by the end of the decade, which should make bacterial meningitis largely preventable.

SECTION II: ENVIRONMENTAL PREVENTION: PROGRAMS THAT WORK

Most of the mild forms of mental retardation have no apparent physical cause, and may be due to adverse environmental conditions experienced in early childhood. According to the American Association on Mental Deficiency, about 89% of all mentally retarded individuals are mildly retarded, and for practically all of the individuals in this category there is no identifiable organic cause of their condition.

The problem is usually ascribed to sociocultural and psychological factors, and requires prevention strategies using knowledge from the behavioral sciences. This is in contrast to the biomedical treatment usually appropriate for the prevention of severe retardation, which is generally ascribed to physical causes.

According to a 1977 "National Multicultural Seminar on Mental Retardation Among Minority Disadvantaged Populations" held in Norfolk, Virginia, such behavioral approaches must deal with the environmental causes of retardation among disadvantaged people. These include dealing with prejudicial attitudes and discriminating practices based on race, ethnic membership or social class. Such attitudes and practices contribute to the impoverished, deprived environment of many low-income and minority people and have a part in the development of retardation in their children.

Authorities in the field of mental retardation suggest some supplemental approaches, which include parent training in child rearing practices, compensatory, preschool, and special elementary instruction based on appropriate theories and techniques.

Parent training should teach the parents the appropriate behavioral management techniques to enhance their children's development in skills, knowledge, and motivation. The preschool phase should give the child the opportunity for social and pre-academic development so he or she can develop normally and be prepared for successful participation in first grade. Finally, the special elementary school program should help the child master language and basic academic skills—reading, writing, and arithmetic—and motivate him to apply these skills with little or no assistance.

Children born and raised in urban ghettos or impoverished rural areas are more likely to be diagnosed as mentally retarded than are children from middle-class suburban neighborhoods. One reason the generally deprived intellectual environment in which such children have been nurtured, combined with numerous other problems linked with poverty: poor nutrition, unhealthy living conditions, poor child care, family emotional problems, inadequate educational programs, and related aspects of deprivation.

Often, minority and low-income children with average intelligence are inappropriately identified as mentally retarded, due to cultural and language differences. The reason, generally, is that public schools tend to use IQ scores to determine intelligence, without taking into account the effect of culture, socio-economic status, language, and environment on these scores. For example, a number of studies have shown that standardized test norms are inadequate for determining intelligence and that the inappropriate labelling of minority children as retarded has serious, adverse affects on their lives.

Unfortunately, some of the studies themselves contribute to the labelling process, since they repeatedly show that minority students, particularly Black and Spanish-speaking, are more apt to be retarded than White children.

Numerous research studies and reports indicate a correlation between mental retardation and minority status and low-income. As they point out, this correlation does not appear to be due to genetic or organic factors, but to the deprived environment in which such children are raised. Their living conditions present increased risks of poor health, infectious and toxic exposures, and low cognitive stimulation. To highlight this situation, at the 1977 National Multicultural Seminar referred to previously, it was reported that 85-90 percent of those who are mildly retarded with no identifiable organic or physical cause were disadvantaged by environmental conditions such as poverty, racial and ethnic discrimination and family distress. Correspondingly, the retardation rates for Blacks, Puerto Ricans, American Indians, and disadvantaged Whites living in urban and rural poverty are especially high.

Poor living conditions may also contribute to emotional problems of mentally retarded people. For example, the Director of the Mental Health and Mental Retardation Center in Philadelphia, found that about 35-50 percent of the mentally retarded clients treated at the center needed mental health care. Most of these were mildly retarded individuals subjected to environmental stresses.

Poverty and minority status are also implicated in the low use of available services for counseling, medical care, and child care assistance, which in turn compounds the problem. Often, low income individuals do not use services, such as perinatal care, that might prevent retardation, because they do not have the funds to do so. Their minority status may isolate them from knowing about available services, or they may have language problems which make it difficult to use the services.

Whereas 75 percent of the majority women seek prenatal care in the first trimester of pregnancy, only 52 percent of the minority women do so. This lack of care contributes to many medical problems, such as malnutrition, toxemia in pregnancy, and prematurity.

In other cases, low income and minority status is associated with retardation because the deprived living conditions provide an unhealthy environment for the pregnant woman, newborn infant, or growing child. These conditions in turn, contribute to a high rate of lead poisoning, maternal and infant infections, malnutrition, and other factors considered in this report's discussion of retardation due to multifactorial causes.

A restricted environment not only hampers development but may also prevent the child's later response to a better environment. There appear to be critical developmental milestones during early childhood on which subsequent development is built. If the child misses any of these important steps, either because he is biologically handicapped or environmentally deprived, he may become more and more developmentally delayed.

This deficiency is related in turn to the poor development of a linguistic system, which is symptomatic of a poorly developed conceptual system and characteristic of the mildly retarded child. Research by the University of North Carolina indicates that children with poor early linguistic development showed improved intellectual functioning after they participated in a developmentally oriented language training program

In some low-income homes, the child's opportunities for learning and adjustment are restricted by such factors as inadequate child care, parental indifference, and a lack of cognitive stimulation in the environment. These homes have few books and play materials, and there is limited verbal interaction, haphazard family routines, and minimal child care and teaching.

Child abuse is another factor which contributes to delayed development and behavior disturbances regardless of income level.

Obviously, severe physical abuse may cause organic damage or even death. But abuse also has drastic psychological consequences since it serves to break the important child-parent bond, whereby the parent serves as model from whom the child wants to learn. Child abuse promotes escape and avoidance behaviors, and denies the child opportunities and incentives for acquiring normative skills and knowledge.

Most of these cases of mental retardation resulting from adverse environmental factors can be prevented through changing the environmental conditions which produce them. A strategy suggested by the National Institute of Child Health and Human Development is to identify the most critical factors in early childhood development, and then to change the child's daily living experience. However, this intervention must come early enough and be comprehensive enough to be effective. In some cases, it must occur almost at birth to prevent secondary retardation from developing.

There are two major environmental prevention strategies: 1) educating the parents about better child-rearing practices; 2) providing environmentally high-risk infants with the stimulation or other elements missing from their environments.

However, in implementing these strategies, program providers must take into account a number of sensitive issues, involving cultural variations, family prerogatives, and parental and child rights, so that services can be provided in a humane, sympathetic, and supportive way, and efforts will not be viewed as bureaucratic interference.

There are numerous programs throughout the country which use these strategies in varying combinations. These include infant stimulation programs and Head Start programs which offer stimulation, parent training, and a combination of parent training coupled with infant stimulation or early childhood intervention. The key element in all of these programs is enriching the child's environment to stimulate his developing cognitive processes and other abilities.

Research has shown that this strategy can work. One of the earliest preliminary studies is the Milwaukee Project, in which researchers identified during pregnancy or soon after, 40 women with below normal IQ scores from impoverished environments. Shortly after birth, the infants were randomly assigned to a control group which received no special treatment or to an experimental group in which the mothers were given occupational, home-making, and parenting training. Meanwhile, the infants participated in an intensive stimulation program, emphasizing achievement motivation, the development of problem solving skills, and language acquisition.

By school age, the stimulated children reportedly had IQ scores averaging 26 points higher than the controls and were far superior in verbal and numerical ability. In fact, their IQ's initially tended to be slightly over the general population average, while the controls tended to be in the dull or mildly retarded range. Unfortunately, comprehensive follow-up reports have never been published.

Other studies have suggested that appropriate intervention will significantly reduce mental retardation if the intervention begins early enough, continues long enough, is intensive enough, and includes the parents, or at least the mother, as an agent of change. Among these is the Abecedarian Project at the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill. The researchers worked with 112 children and six families with low incomes. Not counting attrition by death or biological abnormality, 93 percent of their sample is intact after six years. At this center, they participated in a special curriculum emphasizing linguistic development.

After about one-half of the children completed the preschool program, the researchers found that the educationally treated group had maintained a mean IQ of 98 during the first five years—a score approximately the national average. The control group scored at the national average before 18 months but thereafter, the group's score declined until at age five the mean IQ was 91. The researchers also found that while only 11 percent of the educationally treated group had IQ's under 85, at age five, 39 percent of the controls had IQ's below that level. In addition, the researchers discovered that the effects of stimulation not only increased the measured IQ (itself reflecting linguistic factors) but, also improved the child's general adaptive behavior.

As in other research on the same subject, these findings suggest that the measured IQ of children raised in low-income deprived environments tend to decline in the early developmental years. However, if there is educational intervention with emphasis on linguistic development, the decline is not likely to occur.

Preparation for Parenthood

One type of prevention program directed to the "soon-to-be" parent is designed to help both fathers and mothers be better parents, by showing them how they can foster cognitive and adaptive development in their offspring.

The Indiana State Department of Public Instruction - Innovative Education, developed such a program called *"Prevention: To Be Born and Grow Well,"* which has been used in the State's schools since 1978. The program consists of a curriculum for junior and senior high school students dealing with the causes of mental retardation, and the responsibilities they should assume as parents to lessen the probability of having a handicapped or retarded child.

The program was developed from a survey on what health teachers currently were teaching on mental retardation. As the survey showed, the health educators needed more information on prevention to enhance their teaching. In response, the Indiana State Department of Public Instruction - Innovative Education prepared a detailed curriculum guide for these educators on how students could prevent retardation in their future offspring by taking steps now and when they became parents. The guide also stressed that the male should take equal responsibility for prevention. Traditionally, the role of the male in prevention has been ignored. In addition, the core curriculum consisted of an action checklist with 75 specific prevention techniques which the parent could employ before, during and immediately after the birth of a child. Finally, the guide recommended 168 additional actions to prevent mental retardation during the development years, from birth to 18 years.

Since its publication, the Department has distributed the guide to 5,500 health, home economics, biology, advanced science, secondary special education teachers, and school nurses in Indiana, and has responded to over 900 unsolicited requests from 43 States and 10 foreign countries for copies of the curriculum. Also, the Department has held teacher training workshops in five regions of the State once a year for the two years of the project to prepare teachers to use the curriculum successfully. Approximately 1,100 teachers have been trained as a result.

The curriculum's effectiveness has been pre- and post-tested with about 2,000 participating students in small towns, suburban areas, and cities in Indiana, with uniformly positive results. The students showed an increase of ten to 70 percent in cognitive knowledge for the first section of the curriculum and an increase of 50 to 82 percent for the second section. In addition, when retested after once month, the students continued to show a gain of knowledge ranging from 19 to 59 percent.

Programs for Mothers and Children

These programs involve two main components: 1) preparing the parents to be better parents, by teaching them behavioral techniques to assist their children in accomplishing major developmental tasks; and 2) directly stimulating the child with an enriched environment to enhance development and teaching the parent techniques that can be used at home. The focus varies in different programs.

While some projects are designed for normal children raised in homes where there is a high risk of developmental delay due to family disadvantages, such as a low income or a teenage mother, other programs are for children with handicaps or developmental disabilities. Some are designed for both. Although generally oriented to low-income and disadvantaged children, the underlying approach is beneficial for children of any class or ethnic background.

The following subsections outline specific types of early infant and toddler programs.

Mother Training Programs

Some infant stimulation programs have a training component, in which the mother learns to foster her infant's sensorimotor, cognitive, and language development; provide for

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Infant Stimulation Program, Center for Development and Learning Disorders, University of Alabama in Birmingham.

her infant's health, nutritional, psychological, and educational needs; become aware of her important role as the primary teacher; and to enjoy being a mother.

An example of a successful program of this type is the Infant Stimulation/Mother Training (ISMT) Project at the University of Cincinnati College of Medicine, Pediatrics Division, which uses a model developed and tested at the University of Illinois and at parent and child centers in Illinois and Georgia. In its seven years of existence, it has served close to 1,000 low-income teenage mothers —approximately 80 percent of them minority and 20 percent Appalachian Whites.

Initially, the program was developed to deal with the low-income teenager who is typically unmarried, without a high school diploma, and unable to support herself or her child; and whose own inadequacies contribute to problems of physical, cognitive, and psychological development in the infant. However, the program can easily be used for other mothers with limited parenting skills.

The ISMT program began in early 1973, with the recruitment of 48 mother and infant pairs. The mothers selected from the postpartum unit of the Cincinnati General Hospital were socially disadvantaged, under age 16, and lived within seven miles of the hospital.

Twenty-four of the mother-infant pairs who were assigned to the treatment group participated in a classroom session, in addition to receiving monthly home visits to assess infant development and discuss health and nutrition problems. The other 24 mothers received monthly home visits, but no instruction.

The assumption of the project was that the instruction would make a major difference in helping the young women become more effective mothers. To this end, the classes had three main purposes: 1) to show to the mothers that the way they interact with their infants will affect how their children develop in later life; 2) to encourage the mothers to respond to their infant's vocalizing and other behaviors indicating the infant was either interested in something or was experiencing some stress, and 3) to teach the mothers a sequence of infant development skills, so they could use the appropriate materials to stimulate their child's development.

Mothers began participating when their babies were three to four weeks old and continued until they were 18 months. During this time, the curriculum followed an organized sequence of child development, providing the appropriate stimulation at each stage. For example, until they were

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three months old, the infants were placed in an infant seat, to encourage them to be more attentive to what was going on. During this phase, the mothers were taught to respond promptly to their infant's needs, and to recognize their role as the primary caretaker.

When the infants were about three months old, the teachers urged the mothers to help their babies have new experiences, by interacting with them. As the children got older, the teacher added still more materials to show the mothers additional ways to stimulate the child's mind. Also, at this stage, the mothers learned about the inner forces that lead children to move from one phase of development to the next—such as their drive to become independent, to master their environment, and to fit in socially.

The effectiveness of this approach was shown dramatically when the participating infants were compared to the controls at 12 months. Whereas the infants of the adolescent mothers who only received home visits tended to fall behind in their development, the infants of mothers participating in classes tended to maintain their developmental rate.

After the mothers had attended at least five of the first eight classes, both the mothers and infants showed a greater responsiveness to each other over the eight-week period.

Also, there have been beneficial social effects in the mothers themselves. Most participants decided to return to high school to complete their education and get off welfare, reflecting a desire for self-improvement and potential upward mobility. Since this initial testing phase, this program has continued to operate as a successful established program.

In part, much of the program's success is due to the curriculum design, and the well trained teaching staff. But there are two other important factors: the support mothers get from each other, and the growing responsiveness of their babies, which becomes reinforcing.

In short, teaching mothers to be better parents is an approach that helps to reduce or eliminate delays which often occur in the infants of teenage mothers who lack parenting skills.

Infant and Toddler Stimulation

The Infant and Toddler Learning Program located at the Bronx Developmental Center, (supported by the City College of New York, Department of Social Services, and the Albert Einstein College of Medicine, Rose F. Kennedy Center, U.A.F.) has four major components, which include: 1) a full day/full week educational program for children under three; 2) comprehensive early intervention and treatment services to handicapped children; 3) comprehensive social, psychological, and educational services to the children's families; and 4) the provision of services to an equal number of handicapped and non-handicapped children to help the handicapped children become "mainstreamed" as soon as possible.

The program mixes children from all different economic, social, and ethnic backgrounds, as well as both normal children and children with different handicaps, including Down's syndrome, spina bifida, language delays, sensory impairment, and children at significant risk of retardation, such as those with birth-weight less than 2½ pounds. The children are combined, to encourage delayed children to higher levels of achievement by interacting with normal children.

The trainers are responsive to each child's individual development while also encouraging group interaction, since children learn from each other.

For the first four to eight weeks, the head teacher or coordinator determines the child's current level of functioning, style of learning, and family needs. Tests determine the child's abilities, cognitive level, and ability to understand and use language. In addition, the program staff develops a profile of the child's temperament, which includes information on activity level, bodily functions, responses to new stimuli, and attention span. Also, the staff observes the parent's level of enjoyment and responsiveness to the child. Then, from this broad assessment, the staff determines educational goals and strategies.

From here, the child is gradually phased into the classroom program. Meanwhile the parents are kept involved, by observing their child participate in some sessions and meeting with other parents. Finally, after several weeks of adjustment, the child joins the program on a daily full-time or part-time basis, and is placed in a class based on age and ability.

To maintain parental involvement, the trainers meet monthly with the parents to inform them of their child's development and learn of their needs. Additionally, the staff records each child's progress every three months on a developmental profile and progress chart.

There is also a parents' organization, which features speakers and social events.

Home Teaching Programs for Infants and Toddlers

In addition to programs based in a center, another successful model involves teaching the child at home. This approach has several advantages: parent and child learn in a natural environment; the parent can readily observe the child's natural behavior; it is easier to maintain a desired behavior learned in the home setting; the home is an ideal setting for training the parents, who are already natural agents of change and behavior reinforcement for their child.

A final advantage is that the home teaching program may be the only way to get a developmentally delayed child into a stimulation program, since his parents may lack transportation, cannot afford the cost, or must remain home for other reasons.

The Portage Project used this model. It was a home teaching program for children living in an education service district in south-central rural Wisconsin. During 1972, as an example, it served 75 children from birth to age six. The children had a variety of handicaps, including behavioral problems. They were emotionally disturbed, mentally retarded, physically handicapped, culturally deprived, and/or handicapped in language.

A home teacher visited each child and his family for one and a half hours, one day a week, for 9-12 months. In the interim, the parents taught the child using the prescribed structured curriculum and recording his progress.

The teacher developed an individualized assessment program for each child consisting of developmental skill inventories, intelligence tests, and vocabulary tests. Then, based on the child's present behavior, rather than his disability label, the teacher designed an individualized curriculum using an Early Childhood Curriculum Guide. This Guide presented a developmental sequence which listed 450 behaviors forming from birth to five, in five developmental areas: cognition, language, self-help, motor behavior, and social skills. Based on this checklist, the home teacher determined what behaviors the child already exhibited in each area, and then, using this data, and suggestions from the parents, decided what the child should learn next.

Once determined, this new prescribed learning became the child's goal for the week. Typically, the teacher would decide on one to four goals or prescriptions for each child, and once these were mastered, select another goal or goals. Parents were encouraged to help in setting these goals and in planning the curriculum.

Then, on each weekly visit, the home teacher would demonstrate the behavior to the parent and observe the parent working with the child on the goal. Also, the teacher would evaluate the child's progress each week, and twice a year would give further IQ tests to assess development. Parents would keep a daily activity chart of the child's accomplishments.

The results: the average measured IQ of the children at entry was 75, hence, they might be expected to gain 75 percent of what a normal child would over time, or six months of developmental age in the eight months of the project. In fact, on the average, each child gained 13 months—more than double the expectancy and at a rate of 60 percent more than expected of a child with normal intelligence. A retesting of their IQ's before and after the project also showed a significant gain. On the average, they had a mean gain of 18 points in IQ, as measured by the Stanford Binet Test.

Head Start

The nationwide Head Start Project began officially in the summer of 1965 as part of the Economic Opportunity Act, passed in 1964. Head Start is designed to provide an enriched learning environment in a group setting for children up to age five from low-income families. The aim is to help the children learn concepts, become curious, and be more motivated to learn, so that when they enter elementary school, the can have a "headstart" on keeping up with children from middle-class homes. In addition, the program provides the children with some nutritional and health assistance, and encourages parents to be volunteers to help their own and other childrens' development.

Within this broad framework, individual programs vary widely. For example, while some programs take children as young as three months, others do not take children until they are age two, three or four. In some programs, all of the children participate as a group in a classroom. In others, teachers visit the children at home. In still others, home visits are combined with daily group sessions for the children. In some cases, the program has a tightly structured curriculum, emphasizing school-readiness skills. In others, the emphasis is on children "discovering" what they want to discover in the enriched environment, while influencing their motivation, self-concept, and cognitive diversity.

But significantly, whatever the approach, all of the programs have been successful in improving the learning skills and social adjustment of the children involved. This has been shown by a long term follow-up study, conducted in 1975 by 12 investigators, who independently designed and conducted eight experimental preschool programs in the 60's. Calling themselves the Consortium for Longitudinal Studies, they combined the results of eight original research studies. These findings reversed some of the initially unfavorable data included in the Westinghouse/Ohio Report, which suggested that any early cognitive and emotional gains largely disappeared by the time the children reached the third grade.

The Consortium found 1,600 of the original 2,700 participants. Using IQ and achievement tests and structured interviews, they compared the Head Start "alumni" with children of a similar background who had not attended Head Start programs and selected them randomly as controls. They found several major differences:

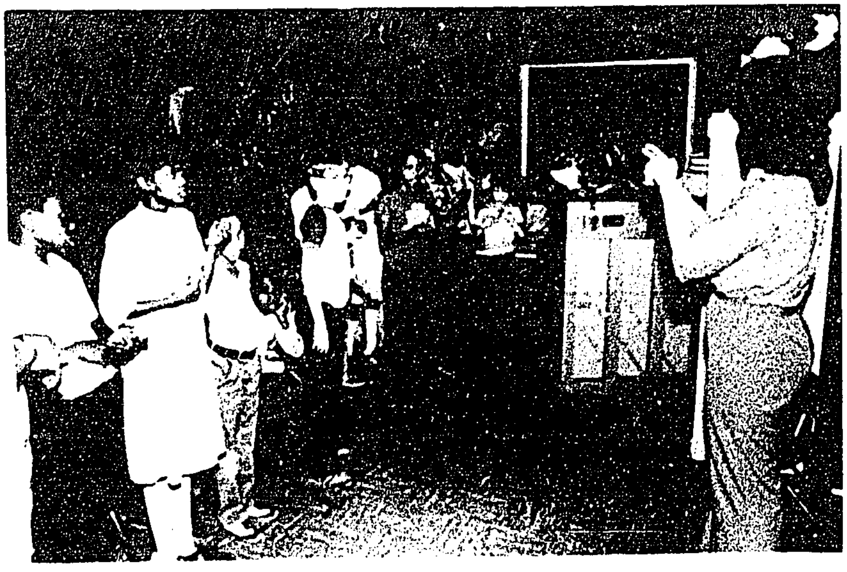
1) The Head Start children were less likely to be placed in special remedial classes when they entered elementary school (only 14 percent of the Head Start children were placed in such classes compared to 29 percent of the controls.)
2) The Head Start children were less likely to be left back or retained in a grade.
3) The Head Start children scored significantly better in mathematics than the controls in a fourth grade standardized test. The Head Start children also tended to score higher on reading.

Obviously, Head Start's success does not lie in a particular curriculum, but in the underlying concept of providing a rich stimulating environment to children who would otherwise not have it.

Elementary School Programs

The next phase of attempting to prevent mental retardation through environmental changes is the elementary shcool. Again, the focus is on assisting children overcome any disadvantage or lack of motivation which may be due to environmental conditions.

The EPIC School (Education Programs for the Individual Child), is a barrier-free school to meet the individual needs of each child. It began in one of Birmingham, Alabama's older schools in 1972, but has been located in its own new facility since 1979. The program serves approximately 500 children from 3 to 15 years of age in grades K through 5. Besides normal or "typical" children, representing 50 percent of the school population, the program has wide variety of atypical students, including physically handicapped, learning disabled, visually impaired, educable mentally retarded, hearing impaired, and emotionally disturbed, as well as gifted children. The curriculum is designed to meet the special needs of typical and atypical children.



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The EPIC School

The school's program is exemplified by a child named Ricky, in pre-school. As the PCMR team reported after the site visit:

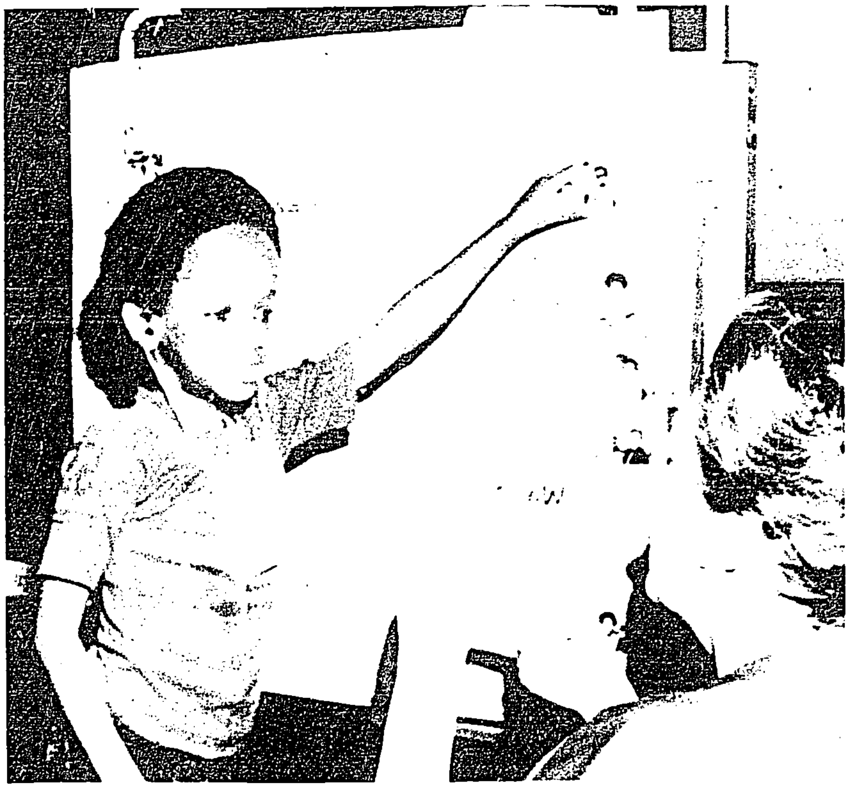
"Ricky just turned five years old in June. We first learned about him when we visited the Center for Developmental and Learning Disorders at the University of Alabama Medical Center. The doctor who told us about Ricky expressed great satisfaction with his progress and development. He was born with an infectious disease known as Toxoplasmosis, which causes deafness. But, exclaimed the doctor, "If you could have seen his eyes when he was born—it was just remarkable. He had a very bright, alert look. Sure, he was sick—jaundiced, wasted, everything. We did not think he would survive. BUT his eyes were always alert. We knew he would make it".

"On visiting the EPIC School the following morning," the PCMR team's report continues, "the first classroom visited was one for hearing-impaired children and to the surprise and delight of the Team, Ricky was there—bright, alert, active and excited about the visitors, specially the photographer. His teacher reported that he is performing at his grade level, despite his severe hearing impairment. His pre-reading, pre-math and writing skills are all at his age level. His speech is coming along as he learns to use his voice; however, he uses sign language for total communication. At home, where he lives with his parents and three-year old sister, Ricky communicates with his mother through sign language." Ricky's IQ is only a little below normal. His major problem is his severe hearing impairment.

The crucial time to intervene with such children is about age one and a half. Ricky was three and a half when he was referred by the Center to the EPIC school.

Ricky's case substantiates the results that can be expected from the interdisciplinary approach to early intervention. An underlying factor is the support personnel, in the medical, social, and psychological fields who were the connecting links to the screening, diagnostic, referral and placement procedures which, finally, placed him in the best available educational setting.

The educational institution created an environment that is conducive to learning, focusing on the whole child rather than the handicapping condition, and setting reasonable objectives.



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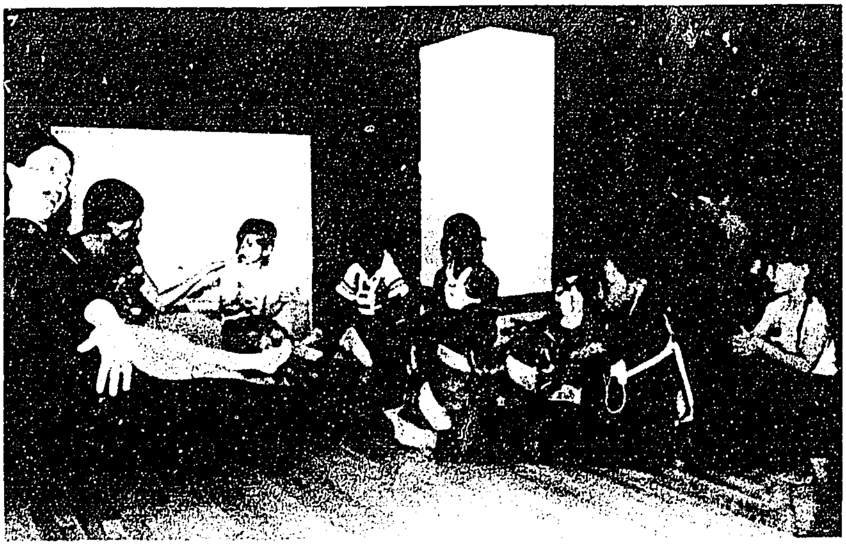
RICKY at the EPIC School.



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The EPIC School

Preschool and Elementary School Research Programs to Encourage Responsiveness

The Juniper Gardens Children's Project provides a setting that encourages responsiveness or active participation as a key to learning. It is a community-based research program located in the inner city of Kansas City, Kansas. Since 1965, it has been under the joint sponsorship of the University of Kansas, a community action group, a local church and civic leaders. The program uses psychologists and educators to work with both preschool and elementary school children to find ways to prevent the high incidence of developmental retardation in inner-city poverty areas through motivating children to improve their social and academic skills. Procedures now widely used were developed to decrease disruptive behavior and increase academic performance of public school students. Research results indicate that inner-city children can be motivated to learn if systematic consequences are provided for appropriate behaviors, such as tokens or specific reinforcers for desired behaviors. For example, researchers found in a series of studies between 1968 and 1977 that they could increase the acquisition of language and pre-academic skills in pre-school children by reinforcers.

Other studies of the project point out the importance of children having the opportunity to respond in class and practice the task. For example, the Juniper Gardens Project also found that pupils made more rapid gains when allowed to plan an arithmetic game (Quizmo) with the principal. Another study indicated that the students participated more and performed better when a question and answer period was restructured so more students could respond. The only change was that the teacher allowed the students up to 15 seconds to respond, instead of five seconds.

The Juniper Gardens research has suggested two key ways in which the school setting can be changed to help prevent mental retardation due to poor learning environment: 1) providing structured reinforcers to promote desired behavior, and 2) providing opportunities for children to respond more actively in the classroom.

Institutions of Higher Learning

PCMR's Prevention Task Group on Environmental Concerns and Minority Affairs (ECMA) in 1976 invited the personnel from 50 colleges and universities to paticipate in a study to identify and define the role of institutions of higher learning in preventing retardation, and suggested that they could participate in several types of endeavors. These included: developing annotated bibliographies, training packages, training films, and curricula; sharing materials with PCMR; establishing interdisciplinary prevention committees to address prevention issues; and encouraging the public school systems to establish pilot programs in prevention.

Then, in 1979, PCMR embarked on a national project to assess the involvement of higher learning intitutions in prevention. The Committee sent letters to 113 colleges and universities, with data sheets indicating the nature of the student population served and the types of programs designed to prevent or minimize mental retardation. There were 49 responses. These data and materials are now being analyzed to determine the appropriate action to be initiated or supported by PCMR to assist these institutions participating in the educational process for prevention.

Key areas where skills and information could be shared include:

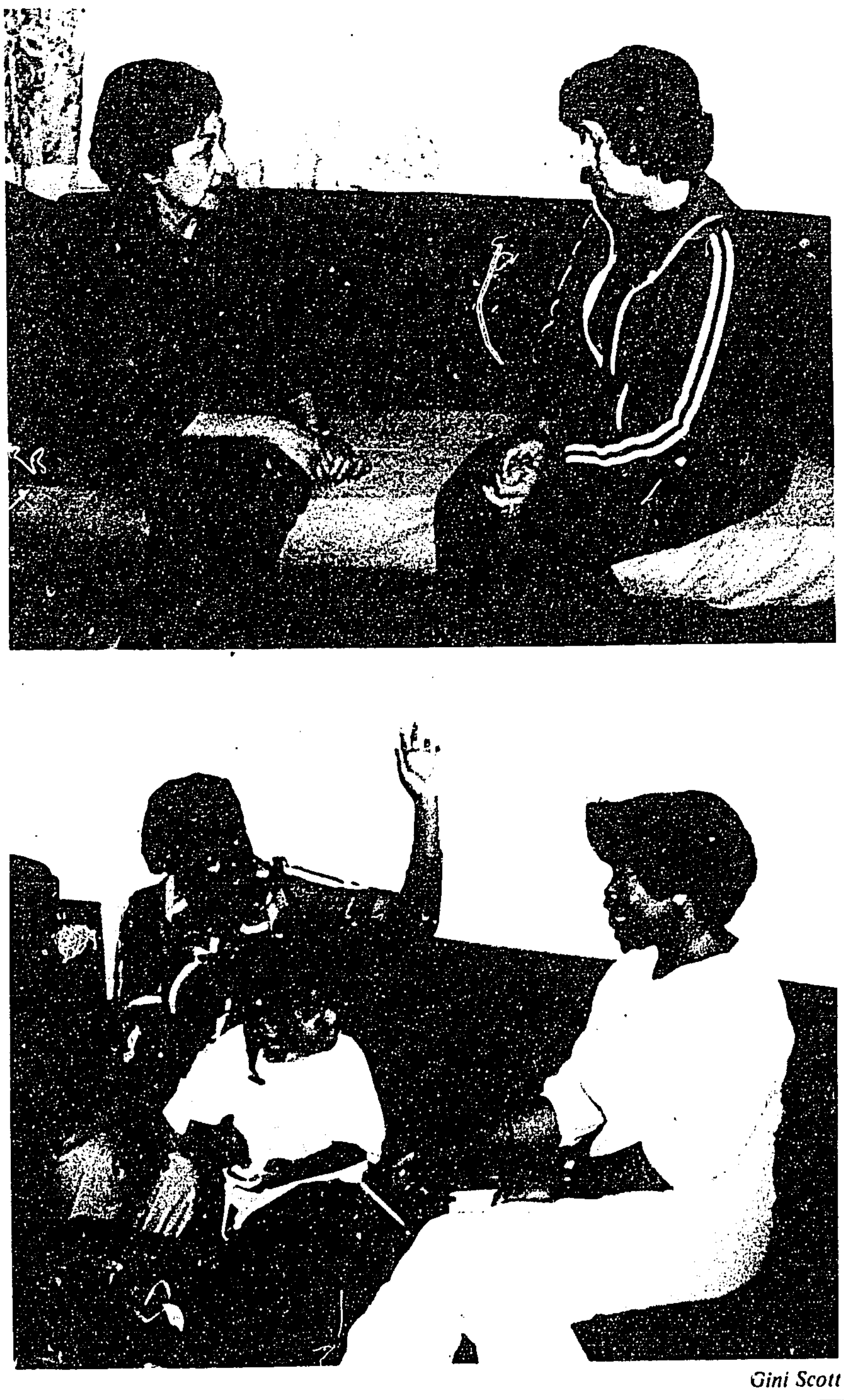
- discussing basic prevention concepts;
- pointing up the sociocultural/environmental and bio-medical etiological factors in mental retardation;
- providing information on genetics, medical technology, nutrition, and child development, bearing on preventing retardation;
- identifying the preventable causes of brain damage due to childhood accidents and other causes;
- discussing the importance of genetic counseling as a prevention strategy;
- providing information on inhibiting the development of neonatal complications due to high-risk pregnancies;
- studying and analyzing programs on safe contraceptive, prenatal, perinatal, and post-natal care;
- identifying the variety of environmental toxins, including lead poisoning and x-rays, which can cause mental retardation;
- identifying the effects of teratogens, such as barbiturates, alcohol, and narcotics on fetal development;
- pointing up how a lack of adequate environmental stimulation due to social conditions or biological problems can curtail the normal cognitive development;
- analyzing the effect of abuse and neglect on intellectual development;
- identifying the metabolic disorders causing mental retardation;
- describing the characteristics of good parenting and suggesting techniques to improve parenting;
- developing good programs for preparing professionals and parents in prevention techniques;
- developing workshops and programs dealing with prevention among the economically deprived and culturally diverse;
- developing programs to help teachers of health, early childhood development, home economics, nutrition, nursing, and related fields better understand the preventable causes of retardation so they can share this knowledge with their students;
- planning special programs for training preservice physicians to help them deal with problems of retarded people.

Project Impact: Helping Low Income and Minority Individuals Prevent Mental Retardation

Project Impact in San Diego, California (one of seven located throughout California, Arizona and Hawaii) is an example of an outreach program designed to deal with the problem of isolation among low-income and minority families. Since 1973, Project Impact has been operating under the sponsorship of the National Association for Retarded Citizens, with funding from the Community Services Administration (formerly the Office of Economic Opportunity).

The project specializes in reaching low-income families with mentally retarded members. Impact reaches into high-risk and high-incidence neighborhoods to identify and link the retarded person and his family with existing community resources.

The San Diego Chapter has two indigenous outreach paraprofessionals, a Black and a Hispanic, who are particularly sensitive to the culture and special needs of the "ghetto" and the "barrio." These neighborhood workers locate families with mentally retarded members through a network of individuals and groups in the community. They work with these families in various ways, such as: counseling them on a wide range of topics, including family planning; counseling on the causes and prevention of mental retardation; informing families of and helping them use community resources; helping families with retarded members organize action and discussion groups; providing transportation and accompanying parents to meetings; negotiating with agencies to obtain needed help; distributing literature on



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preventing retardation; and many other similar services.

A key component of the program is getting parents involved in actively helping their children and joining with other parents in discussion groups to become more aware of mental retardation and ways to prevent it. For example, in San Diego's Spanish-speaking community, the neighborhood worker has helped about 75 parents of retarded children form an organization called El Arbol de la Esperanza—the Tree of Hope. At their meetings, parents arrange for speakers, share experiences, and organize workshops to discuss retardation and prevention.

Also, the members provide families at-risk with prevention literature, in English or Spanish. Some literature points up specific strategies for preventing a variety of diseases and other conditions which may lead to retardation, such as rubella and other infectious diseases, drug and toxic substance poisoning, lead poisoning, and childhood accidents.

Other literature alerts at-risk parents to the dangers of Rh blood disease, metabolic disorders and genetic disorders, and tells them what to do. To reinforce the message of this literature, the neighborhood workers have follow-up discussions on these topics with individual parents and groups.

In part, the program works well because of the support the outreach workers receive from the San Diego County Asociation for Retarded Citizens, which provides staff training on outreach techniques and available services, as well as sponsoring meetings, forums, conferences and training institutes to keep the workers well informed.

In spite of the "hard to reach" label that is often ascribed to many disadvantaged families living in the urban ghettos, the barrios, the migrant labor camps and on the reservations, Project Impact, through its neighborhood worker approach, has demonstrated that these families can overcome their isolation from the mainstream of needed human services.

Taos, New Mexico: Preventing Mental Retardation Among Native Americans

Although data on the prevalence of disabling conditions among Native Americans is sketchy, a number of isolated studies have come up with some startling figures. While exact figures for all tribes are not available, the Indian Health Service and other agencies indicate that 37 percent of young Indian children enter shcool with hearing defects, 25 percent with speech, visual, emotional and other impairments.

These high disability rates come from a variety of causes. For instance, on the Navajo reservation, some causes which have been identified are: a high rate of alcoholism and heavy drinking among pregnant mothers, inadequate prenatal care, poor nutrition, a high prevalence of diseases affecting unborn children, and a high birth rate among women over 35. All these factors substantially increase the risk of a Navajo child's having a physical or mental disability. Similar conditions contribute to the prevalence of handicapping conditions among the Native American population as a whole.

As reported in "He Lifts Up His Head," a report on the proceedings of the Inter-Tribal

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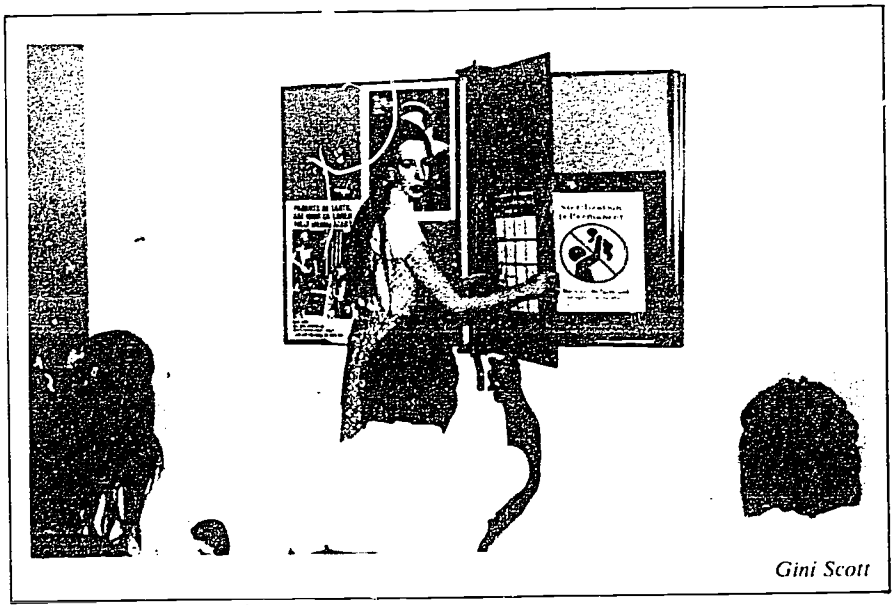

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Symposium on Handicapped Native Americans, 1976, "the apparent prevalence of mental retardation" among Indian students, particularly Navajo, is precipitated by socio-economic and cultural factors, rather than hereditary or psychological ones.

The incidence of genetic retardation among Native Americans does not differ significantly from non-Indians. It is the rate of *functional* retardation and learning disabilities that is inordinately high.

According to a September, 1972 survey conducted by the Bureau of Indian Affairs (BIA) Schools, it is estimated that 19,540 of 49,720 students enrolled in BIA-operated schools were exceptional, that is, children with unusual learning needs. This is approximately 39 percent of the school-age population, compared to a national average of 10-12 percent. Of the estimated 19,540 exceptional children, 3,715 students were reported to have received services, while 15,825 students still needed appropriate special education services.

To deal with the problem of mental retardaton and other conditions contributing to it, some Indian tribes have instituted family planning and Head Start programs, which are designed to take into account the special needs and values of American Indians in order to maximize program acceptance.

One of these programs is at Taos, New Mexico, which is one of 19 Indian pueblos located near the City of Albuquerque. It consists of about 2,000 individuals living in 350 families.

The pueblo's family planning program has been operating since 1976. It receives support from its tribal government to fund a community family planning worker.

In response to local needs, the program is primarily an outreach effort, in which the family planning worker meets with women and teenagers in their homes, in groups, and in other settings to explain the advantages of family planning and to give advice about child care, nutrition and health, as related to preventing mental retardation. Meeting with individuals privately and informally and developing trust are also important components of this program (most Indians are very sensitive about family planning and do not want to be seen going to a health center to get such counseling). There is little privacy because everyone in the pueblo knows everyone else. Therefore, it is important to work with each client in strictest confidence.

The family planning message is presented to take into account Indian culture and values. Since children are highly valued, instead of suggesting that the women have fewer children, which would be an objectionable idea, the family planning worker emphasizes the importance of spacing, so the women can better care for the children they have and thereby lessen the risks of problem pregnancies.

Because teenage pregnancy has been a major problem on the reservation, special efforts have also been made to adapt the program to this age group, who are typically shy about seeking family planning information and highly responsive to peer group pressures. Thus, the worker makes

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it a point to assure teenagers that their privacy in discussing their sexual behavior will be respected, and carefully avoids a moralist approach in paticular to out-of-wedlock pregnancy. Instead, the consequences of any early pregnancy are stressed, so that teenagers fully understand the health risks involved.

Highly important to this program is the professional back-up and support the family planning worker gets from medical personnel in the Taos Indian Health Center, who offer a full range of outpatient gynecological services, including medical check-ups, genetic counseling, pelvic examinations, pap smears, breast examinations, venereal disease screening and voluntary methods of family planning.

Persistence has also been a key to success. Family planning is a new concept for the Taos Indians, and the worker has had to change attitudes to gain program acceptance. But through patience and understanding, community members have come to trust the family planning worker and her approach.

The result has been a reduction in the fertility rate on the Taos pueblo. According to the New Mexico Family Planning Council's Newsletter, *The Sage, for Spring, 1980,* the fertility rate in Taos dropped below the national average of 54.5 babies per 1,000 women, whereas, the rate for New Mexico generally is 72.3 per 1,000 about 50 percent above the national average.

The other major prevention program on the pueblo is Headstart. The program is designed to provide a rich stimulating environment for children three to five years of age to encourage their development and avoid the possibility of retardaton due to a restricted early environment. It currently serves 27 children a year who are supervised by three teachers.

After the children are enrolled in the program, the teachers engage in extensive outreach in the community to encourage parents to stimulate their children and to identify any problems in the home that may lead to mental retardation. They follow up with the parents to see how their children are progressing, and if they observe any signs of retardation or delayed development, they have health representatives visit the children. Also, they give the parents suggestions on how to stimulate their children at home. The school additionally prepares a monthly newsletter for parents with other ideas on stimulation techniques.

The result has been high community interest in the program, and widespread parent involvement in providing their children with added stimulation. For example, several parents volunteer as teacher's aides, and share songs, stories, and other elements of Indian culture with the children, in addition to using techniques learned through the school to stimulate their children at home.

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SECTION III: MULTI-FACTORIAL CONDITIONS

In many cases, mental retardation is caused by a combination of biomedical and environmental factors. This occurs when the environmental conditions contribute to the individual's greater exposure to biomedical causes of retardation. For example, the risks of retardation are much higher for the low birth-weight premature infant than the normal infant, and this situation can be regarded as a biomedical cause, since prematurity can result from a variety of biological factors, including genetic defects. However, when the risk of prematurity and low birth-weight babies is higher in certain population groups, an environmental factor is added onto the biological condition.

An example of this interaction of biological on environmental effects is the problem of teenage pregnancy, since they are more likely to have premature/low birth-weight babies than others. Likewise, mothers who have inferior nutrition during pregnancy are more likely to have such a child. In turn, retardation due to combined effects can be prevented by efforts dealing with both types of causation. For instance, the biomedical approach to the problem of prematurity in teenage pregnancy involves treating the premature infant through intensive care techniques. The environmental strategy involves working with the teenager to reduce the likelihood of such a pregnancy occurring. Similarly, both biomedical and environmental approaches can be used to reduce retardation in the low birth-weight infants of malnourished mothers. The biomedical approach involves giving that offspring the best possible care, to enable it to survive in the perinatal period. The environmental approach involves assisting the pregnant woman prior to birth with improved prenatal care, which includes better nutrition.

Teenage Pregnancy

According to the Alan Guttmacher Institute an estimated one million teenagers get pregnant each year, and according to the Chairman of the Scientific Advisory Board of the Joseph P. Kennedy, Jr. Foundation, the teenage mother under 16 is less likely than the older mother to have a normal baby. About 15 to 18 percent of the babies of adolescent mothers are low birth-weight. Also, due to the numerous stresses faced by the adolescent mother, child abuse leading to retarded development and/or even brain damage is much more frequent among the offspring of teenage mothers than of mature mothers.

Johns Hopkins University reports in "A Comprehensive Approach to Adolescent Pregnancy", that the number of teenage pregnancies throughout the United States has been increasing dramatically, in part because of the growing acceptability of premarital sexual behavior, and the susceptibility of adolescents to peer pressures and opinion promoting this behavior. Also, adolescents frequently lack the information necessary to prevent pregnancy or to be adequate parents when they do have children.

In 1978, in recognition of this growing problem, the Adolescent Pregnancy Care and Prevention Act was passed by Congress which provides family planning services to teenagers who want them at no cost. However, even with the availability of services, many teenagers do not use family planning, out of ignorance or because they fear parents or friends knowing about their activities and because family planning services in a clinic for older women do not meet their needs.

The situation is unfortunate, not only because the pregnancy may interfere with the teenager's school and career plans and social life, but also because teenage pregnancies are much more likely to have unfavorable outcomes compared to the pregnancies of older women. As a group, adolescents are more likely to experience pregnancy complications such as anemia and toxemia, have premature, low birth-weight, or growth-retarded infants, and deliver babies that have a higher death rate in the perinatal period and as infants. Also, they are more likely to give birth to babies who will later show lower intellectual development.

Additionally, adolescent pregnancy is associated with other risk factors that can detrimentally affect the quality of life for the teenage mother, her child, and her whole family. This was shown in an 8-12 year follow-up study of a large population of urban mothers, their children, and their families conducted by Johns Hopkins University. Of the 4,557 mothers included in the study, 702 became pregnant as adolescents and 668 had live births. The study followed the surviving children until they were eight, and subsequently 416 children were studied at age 12. To examine the problems associated with teenage pregnancy, the researchers compared the teenage group with a group of women ages 20-24, since this latter group is generally considered to have the best pregnancy outcome.

The results showed that the teenagers were more likely to have problems directly associated with the birth itself, and were subsequently more likely to provide a poor environment for their children. More specifically, the research results were that:

- Teenagers were more likely to be school drop-outs. (Whereas 77 percent of the mothers 20-24 graduated from high school, only 35 percent of the teenagers did.)
- Teenagers were more likely to be dependent on welfare. (Whereas only 44 percent of them were in families that were self-supporting 12 years after delivery, 71 percent of the other mothers were self-supporting.)
- Teenagers were likely to have greater instability, indicated by a high frequency of single parent families, divorce, death, and change in status. (Whereas 37 percent of the teens had three or more status changes in the 12-year period, only 4 percent of the older women did.)
- Teenagers were more likely to suffer fetal loss (46 percent compared to 26 percent among the older women).

Other research has widely reported that teenagers have a higher proportion of still-births, spontaneous abortions, premature births, low birth-weight births, and infants born with developmental disabilities, including mental retardation.

To deal with this problem, various hospitals, family planning centers, clinics, and other organizations have developed prevention programs targeted for the teenager. Generally, the programs have two components—one designed to provide the teenager with contraceptive and other family planning information, so she can avoid the pregnancy in the first place; and one to assist the already pregnant teenager so she can give birth to a more healthy baby and provide better care for it after birth.

Besides providing specific services, to be successful these programs have to consider several factors about adolescents generally. For example, teenagers tend to be poor users of health care facilities, and generally lack information about health, nutrition, reproduction, contraception, parenting, child development, child care, and where to go to get assistance with social services, employment, day care, and other services. Also, most seem to fear using clinic services, and rarely participate in programs on a regular basis, particularly in programs designed primarily for older women. Thus, special arrangements have to be made to adapt the clinic to adolescent needs, so they will use it.

An example is the St. Paul Minnesota Maternal and Infant Care (MIC) Project, which has provided comprehensive, multi-disciplinary health care to adolescents since 1968. Part of the project has included two junior and senior high school-based clinics, which, since 1973, have offered various family planning services, along with counseling on nutrition, prenatal care, and other educational services.

In a 1976 follow-up study, the researchers found over the three-year period that 25 percent of the female students came in for services, and after three years, 87 percent of them continued to use contraceptive techniques. Even more significant is that in those three years the teenage pregnancy rate declined 40 percent and the teenagers who did have babies had a lower incidence of obstetrical problems and healthier infants. Since then, use of the service has increased, so that in the 1978-79 period, 75 percent of the students used the clinic.

According to the researchers, the program was successful because the teenagers were provided with free services within a school to which they had easy access; and they could use them in confidence, since parental consent was not required. The services were provided as part of a generalized health program.

At Johns Hopkins, another successful program designed for teenagers was carried out in a hospital, beginning in 1974. This program included several major features:

- High quality medical and obstetrical care throughout pregnancy to detect any problems early and deal with them as they developed. If required, high-risk fetal monitoring, and intensive prenatal care was available.
- Social, psychological, and educational/vocational counseling, to help the girls with adjustment problems, and encourage them to remain in school.
- An intensive health education program to provide participating teenagers with the health information they lack, in human sexuality, reproduction and contraception, sexually transmitted disease, nutrition, general health care, toxic substances such as cigarettes and alcohol, delivery and labor, early child development, and parenting.
- Special nursing services to assist the mother during labor and delivery including counseling, educational group sessions, and newborn screening as well as regular nursing services.
- Nutrition education and food supplements available to most adolescents through the Women, Infants, and Children (WIC) Program.
- Telephone consultation hours so the mother can contact on-call a pediatric nurse practitioner for assistance with the baby.
- A postpartum well-baby visit four weeks after delivery, to screen the mother and child for any abnormal conditions; provide child care, feeding, and parenting advice; make needed social service referrals; and provide family planning services.

Thereafter, follow-up services are continued for three years to make sure all is progressing well.

The results have indicated that teenagers participating in the program have had a reduced rate of premature births and healthier babies. For example, only ten percent of the babies were premature, and only 2.5 percent small for gestational age. Also, only five percent became pregnant again within one year, which is only 1/5 the 25 percent rate for teenagers nationally, and 1/10 the 47 percent rate reported in the same urban population ten years earlier.

Teen Tot Clinic

Another program example is the Teen-Tot Clinic located in Children's Hospital at the University of Alabama Medical Center since May, 1978.

The clinic is designed to ameliorate the problems of teenage pregnancy and the high potential of retardation in these infants. The multi-disciplinary staff provides the teenage mother with various types of assistance:

- education on child-care and parenting skills;
- help with personal adjustment to become a better parent;
- medical aid for their children, including well-baby examinations, immunizations, developmental tests, nutritional assessment, and treatment for illness;
- contraceptive counseling to help in future planning.

In 1979, out of approximately 500 eligible teenagers in the county, the clinic saw 120 mothers, 85 percent of them Black and 15 percent White. The vast majority, 85 percent, were single. For 60 percent, the baby was unplanned.

In many cases, the clinic provided specific services to prevent mental retardation. For example, clinic staff placed over 91 percent of the mothers on the WIC program during pregnancy, and provided 95 percent of their children with WIC supplements. Also, the staff carefully monitored 20 percent of the children who were born prematurely, and hospitalized 21 percent of the children for various problems, such as jaundice, pneumonia, and meningitis related to infant infection or premature birth.

The staff counsels the mothers on how to take care of their babies, and provides guidance for adolescent mothers *and* fathers to help promote their optimal functioning both as parents and as individuals. Peer interaction, opportunities for socialization, and experiences with other adolescent mothers and fathers are encouraged. The staff assists parents with their decisions regarding educational, employment, living arrangements, and personal goals and relationships.

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Nutrition

Poor nutrition for both the baby and mother is linked to impaired brain development and reduced intellectual performance. Numerous studies with animals and humans have repeatedly shown this relationship. The data is most impressive in cases of severe protein malnutrition.

For the developing fetus, the mother's nutrition is especially critical, since it not only may affect brain development of the fetus, but it also influences the birth-weight of the baby - both conditions associated with mental retardation, and other problems.

The Surgeon General's report for 1979 states that a low birth-weight is the greatest single hazard for infants, since it increases the infant's vulnerability to developmental problems and death. Infants less than 2500 grams at birth are 20 times more likely to die within the first year. Of all infant deaths, 2/3 occur in those weighing less than 2500 grams. Low birth-weight infants that survive are ten times more likely than normal infants to become mentally retarded.

Nutrition, in turn, plays a major role in the prospects of the infant, since a poorly nourished baby is likely to have a low birth-weight, as shown by numerous studies, including those conducted at the Institute of Nutrition at the University of North Carolina at Chapel Hill.

Unfortunately, poor women frequently have trouble obtaining proper nutrition during pregnancy, because they lack the financial resources or eat the wrong kinds of foods. Numerous studies of low-income women in the United States and in other countries have shown this, and the problem of malnutrition leading to birth defects in developing Third World Countries is well known.

In recognition of the relationship among poverty, poor nutrition, low birth-weight, and developmental problems, the U. S. Congress authorized the Special Supplemental Food Program for Women, Infants, and Children (called WIC) in 1972, and extended this in 1975 through 1982. The program provides food supplements of milk or cheese, eggs, cereals, and fruit juices, to low-income women who are at nutritional risk. In 1979, $550 million was allocated to this program which served approximately 200,000 women in that year. However, it is obvious this program could do more, since 1,300,000 were eligible to participate.

In 1978, the American College of Obstetrics and Gynecology developed a list of specific risk categories, where the mother might be expected to have a growth-retarded baby. These include: The age of the mother (below 16 or above 35): rapid, consecutive pregnancies within two years; a previous history of poor pregnancy outcome; an inadequate income to purchase food; being a food faddist, heavy smoker, drug addict, or alcohol abuser; having a chronic systemic disease; or being seriously under- or overweight. A pregnant mother with inadequate weight gain would also be considered at nutritional risk.

Such risk factors should be taken into account in planning a nutritional program for the pregnant mother. In addition to determine nutritional deficits her current dietary intake over a 24-hour period should be evaluated to develop a profile of major nutrients, food choices, and food frequencies. The development of computer-assisted techniques will make this kind of evaluation possible. Additionally, this profile can be supplemented by using a portable ultrasound instrument to indicate the woman's bodily composition of fats and muscles. These two profiles—food usage and bodily composition—could provide a complete picture of a woman's nutritional status and needs.

Besides maternal nutrition, the nutrition of the newborn infant and child may also be crucial to preventing developmental problems and mental retardation. This problem is particularly critical for low-income mothers, who have a major difficulty providing their child with the proper nutrition after birth, due to cost constraints. For this reason, the WIC program provides supplemental foods to infants and young children up to five, as well as to pregnant women.

Another strategy that may have a role for preventing mental retardation in infants, regardless of background, is breast-feeding. Today, most mothers use a formula soon after birth, and only about five percent of the mothers in the U. S. use breast-feeding for the first year or two of life, when the child can be weaned to solid food.

However, many researchers recommend that breast-feeding be continued since it both provides the infant with key nutrients, and protects it against infections that can cause illness and retardation. The Department of Pediatrics at Rainbow Babies and Children Hospital in Cleveland, Ohio, points out that even though overall infant mortality has dropped sharply in the last few decades, breast-fed babies have a lower incidence of respiratory and diarrheal diseases, and are less likely to suffer from serious neonatal infections and allergies than are bottle-fed babies.

Breast-fed babies thrive so much better because breast milk contains many protective anti-infectious elements not found in cow's milk. In addition, breast-feeding provides the infant with other advantages, such as the warmth and stimulation of the mother, factors which can contribute to a more secure, responsive infant. Also, breast-feeding helps the mother develop a better attachment to her baby, and this relationship may contribute to better child care later on.

Lead Poisoning

A serious and clearly preventable cause of mental retardation and other developmental problems is lead poisoning. While it can affect adults as well as children, its effect on the young child is particularly severe, and children between the ages of one and six are more often the victims. According to a Baltimore study, about 500,000 individuals each year are affected.

Victims are likely to live in low-income neighborhoods where there is increased chance of exposure to lead poisoning. High-risk areas are the inner-city where old houses are deteriorating, near congested highways, or near plants producing lead products.

The major source of lead and the most common cause of poisoning in children is the flaking lead-based paint on the interior and exterior of old dilapidated houses. By eating the peeling paint, which has a sweet taste, children are poisoned.

Many other sources of lead which can cause poisoning include lead particles in the air, and in dust, dirt, and soil. Lead can also appear in food if animals ingest it; or if used in processing, it may turn up in water, newsprint, and paper containing colored ink, like comics; in improperly fired ceramic items; plumbing; glassware, toys or furniture painted with lead-additive paints, and in other products. Factories manufacturing lead-based products produce lead fumes and dust as a byproduct, which can end up in the air, water and soil.

The exhaust from an automobile using lead-based gas also releases lead into the air, from which it falls to contaminate roadways and the soil in which children play. In fact, a study by the Environmental Protection Agency indicates that most airborne lead comes from automobiles using leaded gasoline - about half of the autos now in use. The remainder, about 10 percent comes from industrial sources, such as smelters and paint factories.

In certain high-risk areas, such as the inner-city or areas near some types of industry, the problem is especially serious, and tests of residents have indicated high lead-levels in their blood. This finding has significant implications, since lead accumulates in the body, and above a certain blood level, depending upon the individual's age and other factors, symptoms of lead poisoning appear.

At first these symptoms may be misleading. In the early stages they resemble those of other illnesses; thus, lead poisoning may not be suspected until serious and irreparable damage has occurred. For example, some of the early signs are loss of appetite, stomach aches, headaches, tiredness, crankiness, and clumsiness which might suggest many less serious diseases or just a general debilitation. But if the individual is tested through a lead screening test, the condition can be clearly identified at this stage and treated successfully.

Children with milder lead poisoning develop visual motor deficits, a short attention span, restlessness, easy distractability and impulsiveness. In its more serious form, lead poisoning leads to recurrent vomiting, dizziness, convulsive disorders, cerebral palsy, blindness, coma, and mental retardation. Once damage occurs to the brain or nervous system, there is no way to reverse it.

Lead poisoning may result in reduced intellectual functioning in mild cases of ingestion without overt clinical symptoms. Researchers reporting in the New England Journal of Medicine in 1979 compared the performance of 58 children with high dentine lead-levels to 100 children with low dentine levels in Chelsea and Somerville, Massachusetts. The researchers found that the children with high lead-levels performed significantly less well on the Weschler Intelligent Scale, particularly on the verbal items, and on other measures of auditory and verbal processing and attention. They also behaved poorly in the classroom, according to teachers' ratings.

Other studies have shown the association between lead poisoning and low-income areas with deteriorating houses. As an example, a 1974 study measured the dentine lead-levels of children in two school districts in Philadelphia—one serving an area with newer homes and primarily middle-income residents, and the other serving primarily Black area with dilapidated housing. As expected, it found the dentine level much higher in the high-risk area, where 20 percent of the children had levels in the toxic range.

Workers in industries working with lead-based products have also been found to have a higher than average risk of poisoning since they are likely to inhale lead fumes into their lungs, or get lead dust on their clothes, which may contaminate their home, adversely affecting their children.

These examples show the problem of lead poisoning is widespread and serious. But, it can be prevented. There are two key strategies. One is to eliminate the hazard; the other to screen at-risk individuals, to determine if they have higher than normal blood levels, indicating they are in danger of poisoning. Then, steps can be taken to prevent subsequent exposure.

Some efforts to eliminate the hazard can be taken at the individual level. For example, parents can be alerted, so they are aware it is dangerous, especially for children, to eat paint or play in areas with a high concentrate of lead in the soil. Plant managers can use techniques like air monitoring to determine the lead-level in the air and decide when there is an unacceptable build-up. They can also institute practices to reduce the amount of lead in the plant, such as isolating more hazardous operations from the general plant area, and avoiding practices that create dust clouds.

However, other steps to eliminate the hazard involve a broader effort, in which the whole community or government must get involved. For example, the Department of Health and Human Services estimates that over 40 million deteriorating homes were built prior to 1950, and the problem of flaking lead paint creates a serious hazard. According to Department statistics, five to seven million of these homes are immediate hazards because of their poor maintenance.

Some government agencies have taken some steps to deal with this massive problem. For instance, in 1971, Congress passed the Lead-Based Paint Poisoning Prevention Act, which authorized DHEW (now DHHS) to help communities develop and carry out screening and treatment programs, and eliminate the causes of lead paint poisoning. The Act also prohibited the future use of lead-based paint in residential structures constructed or rehabilitated by the Federal government or using any form of Federal assistance. Finally, the Act authorized the Department of Housing and Urban Development to establish procedures to eliminate immediately the hazards of lead-based paint in housing under its jurisdiction. The Department was further instructed to notify tenants and purchasers of assisted housing constructed before 1950 about the potential hazards of lead-based paint.

Another step in the fight against lead poisoning is recent legislation requiring new cars to use lead-free gasoline to reduce airborne lead. But still, much needs to be done on a massive scale to reduce or eliminate the risks of poisoning from industrial wastes.

Besides efforts to eliminate the hazard, the other major prevention approach is screening to identify an individual suffering from lead poisoning, even before the condition becomes symptomatic. There are two major screening techniques: one, which involves determining the individual's level of lead in the blood, measures lead absorption; the other test, which uses dried drops of blood collected on Guthrie filter paper, is called the EP test (for erythrocyte protoporphyrin screening) and measures the individual's level of lead toxicity.

In either case, once an individual is identified, he can be removed from the hazard, and, if any symptoms have started to develop, he can be treated for them. Since the symptoms don't usually appear until three or more months after exposure, and result from a gradual build-up of toxicity, screening is particularly important to identify an individual at risk.

The value of screening is shown in the high number of poisoning cases identified. For example, in a screening program carried out in five New York institutions, the tests showed that 4-13 percent of the individuals were affected. In a 1970 survey of a high risk area of Norfolk, 20 percent of the children from one to six had elevated blood levels.

Many lead poisoning prevention programs use screening as an essential component. One example of this is the Norfolk, Virginia Childhood Lead Poisoning Prevention Program, which has been operating successfully since 1970. The two major program features are the early detection through screening of children with high level of lead absorption, followed by effective medical and environmental intervention.

Other components of the program include:

- An educational and outreach program to make members of the community aware of the danger and prevalence of childhood lead poisoning;
- An advisory board of community members which assists the program staff in planning and executing program activities. The board also serves to gain citizen support;
- Contact with other city health, environmental, and legal agencies to improve and enforce city codes related to health and housing which impact on the prevention of lead poisoning;
- A follow-up medical action program for children at risk to reduce the child's exposure to lead and provide general pediatric care, health education for family, hospital therapy when appropriate, and a corrective for nutritional deficiencies which exist;
- A comprehensive housing management system to investigate suspected dwellings, reduce or remove lead hazards, and assist homeowners who are in financial difficulty to reduce or remove the hazard.

Since the beginning of this comprehensive prevention program, about 65,000 Norfolk children and 1,000 adults have been screened, and 3,000 houses inspected. Due to these efforts, about 300 children were hospitalized after lead poisoning was discovered, and no Norfolk child has died of lead poisoning since the program began. In short, lead poisoning can be prevented through a combination of medical and environmental approaches designed to reduce the hazards of exposure, and to quickly treat the exposed individual while there is still time.

Problems Related to the Effect of Alcohol, Drugs, Teratogens, and Mutagens

Another major source of retardation comes from the effect of alcohol, drugs, and noxious substances in the environment and work place. Some substances called mutagens, can change the genetic structure of the reproductive cells in either men or women before conception takes place, resulting in abnormally formed offspring. Some industrial chemicals and radiation are among the mutagens.

Other substances, called teratogens, are birth defect-causing agents, which act directly on the fetus after conception. Among them are methyl mercury, pesticides, x-rays, and anesthetic gases. These have a wide range of effects on the fetus, ranging from malformed organs to poorly developed bodily structures, depending upon the fetal stage of development at the time of exposure. In most cases, the first trimester of pregnancy is the most critical period when teratogens have the most detrimental effect, since this is when the organs are developing. But this is not true for all teratogens. For instance, radiation causes a continuum of effects, depending upon the stage of gestation when exposure occurs. In the first phase of development, it usually kills the embryo. In the first or second trimester when the brain is developing rapidly, exposure can result in microcephaly and mental retardation. In the third trimester, the effect of exposure is usually a low birth-weight baby.

In many cases, the effect of a particular teratogen on the developing fetus produces certain well known syndromes or patterns. Occasionally, a substance affects the genetic structure of the parents, too. For example, radiation acts as a mutagen, which acts directly on the chromosomes to change them. But it also interferes with fetal development by disrupting DNA synthesis and cell replication in the fetal brain, leading to microcephaly and mental retardation in babies exposed to radiation during pregnancy, as occurred subsequent to exposure to atom bomb explosions.

The reason that alcohol, drugs, and other teratogens have adverse effects on the developing fetus is that many teratogenic substances are transmitted to the fetus through the placenta, by way of the mother's bloodstream. Thus, anything that has a detrimental effect on the mother's blood chemistry or metabolism, such as teratogens, can directly or indirectly damage the developing fetus. The most dangerous period is usually the first 12 weeks of pregnancy, when the baby's body, arms, legs, internal organs, and brain are being formed. After this critical period, the same teratogens may not have any effect.

One of the most common problems in this category is the fetal alcohol syndrome, which may affect the unborn infant of a pregnant woman who drinks. The affected infant will generally be born small, especially in head size; have malformed facial features, such as narrow eyes, low nasal bridge and short upturned nose; and will generally be poorly coordinated and mentally retarded. About half have heart defects. For adolescent mothers who drink, the problem is even more serious, since they are more apt to have premature low birth-weight babies.

Narcotics addiction in the mother can lead to addition in the infant, as well as producing a sick baby, who undergoes withdrawal symptoms. Furthermore, narcotics addicts tend to neglect their own health. Cigarette smoking, also, can have damaging effects since mothers who smoke heavily tend to give birth to low birth-weight babies, and such babies may have learning problems. Smoking mothers also have a high rate of spontaneous abortions, and cigarette smoking can stunt the growth of the fetus and deprive it of adequate nutrients. The greatest danger is during the second half of the pregnancy, when the fetus is undergoing the greatest growth.

Other teratogens which can cause mental retardation in the fetus by affecting the parents' reproductive cells or acting directly upon the developing fetus are found in the environment and work place. These currently constitute the largest and most serious source of defects due to teratogens.

For example, both males and females working with anesthetics are at high risk of having defective offspring. The direct exposure of women doctors or nurses to anesthetic gases is associated with a higher incidence of infertility, spontaneous abortion, still birth, low birth-weight, and congenital malformation than the average. Women married to male anesthetists are at-risk for having abnormal infants.

Other studies have found that carbon monoxide poisoning is associated with fetal death and severe brain damage, although the effects of low level carbon monoxide, such as experienced by individuals working around automobile exhaust fumes, is uncertain.

Although many of the studies on environmental hazards have focused on the effects on females, some have shown that males are at-risk, too, because some teratogens have a detrimental effect on sperm cells. Ironically, the result of this effect is that males have a higher chance of passing on a chemically induced mutation to their offspring than females, since sperm production involves the mitotic division of cells throughout the male's reproductive life.

Other implicated substances include numerous metals, such as lead, metallic mercury, cadmium; organic chemicals, such as formaldehyde, pesticides, methyl mercury, polychlorinated biphenyls, dioxin, DDT, and many gases.

Some researchers have tested these substances with animals and have produced retardation in their offspring. For example, in 1974 an investigation of the effect of lead on sheep fetus found that the lead crossed the placenta into the fetuses, and impaired the offspring's subsequent learning ability.

However, because the fetus and mothers are exposed to many substances in the environment simultaneously, it is often difficult to identify a particular causal agent, and thereby determine cause and effect relationships between particular teratogens and fetal abnormalities. This problem of identification and specifying causes complicates the development of prevention strategies.

Also, prevention is complicated by other factors. In many cases, it is difficult to avoid exposure, since the likelihood of being exposed to various hazards in the environment and work place has increased, because the number of processes producing these teratogens has increased.

Workers, for example, are exposed to toxic substances not only when they work in nuclear and chemical-related occupations, but also in many commonplace activities such as toll-booth attendants, hospital workers, hairdressers, the Love Canal residents in New York. etc..

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To deal with the variety of problems caused by teratogens, prevention strategies may involve genetic counseling, amniocentesis, or fetal monitoring to identify parents at-risk and determine if their fetus is developing normally. However, broader prevention strategies are also being investigated by the National Institute for Occupational Safety and Health, the U. S. Environmental Protection Agency, and other organizations to consider ways of cleaning up the workplace and the environment to reduce the risk of exposure.

Accidents

Another biomedical/environmental source of mental retardation that can often be prevented is childhood accidents. These accidents can cause mental retardation as a result of trauma to the brain, which produces irreversible damage.

As the national statistics show, accidents kill and injure more children in the United States than any other single cause, after the first critical months of infancy. Some examples of accidents include electric shocks from exposed outlets and frayed electric cords; burns from boiling water or items cooking on a stove; falls from windows and down stairs; ingested medicines from the medicine cabinet; etc. But the greatest number of accidents involves the automobile, which causes more deaths and permanent injuries from accidents than all other types of accidents combined. Ironically, 90 percent of all childhood accidents can be prevented according to the American Academy of Pediatrics, just by exercising caution to prevent the occurrence of the accidents in the first place.

This caution is particularly applicable in the case of automobile accidents, since the use of a seat belt can prevent serious injury or death in the event of most sudden stops or crashes. But, according to a 1979 paper issued by the U. S. Department of Transportation, 93 percent of all children under age ten travel without any restraints. If they did have restraints, many deaths and injuries could be prevented.

According to the Department of Transportation, if all children under the age of five were restrained at the time of an accident, the number of deaths could be reduced by 91 percent and the number of injuries by 78 percent. Without a seat belt, any sudden stop at 30 miles an hour or more can project a child through the windshield with as much force as if the child had fallen from a third-floor window. Similarly, a crash at 20 miles per hour or more is likely to hurl the child through the windshield or thrust him against the dashboard. Because of the force in either case, no adult will be strong enough to restrain him. As a result, the child may be killed in such an accident or suffer severe brain damage leading to mental retardation. However, a well designed restraining device appropriate for a child can prevent this tragedy.

Unfortunately, many adults do not exercise these precautions. To get them to do so, some communities have developed prevention programs to alert them to the dangers, and to accident prevention strategies.

One such program is the Ukiah Car Safety Campaign, sponsored by the Ukiah Valley Association for the Handicapped and the Prevention Committee of the Mendocino County Council on Children and Youth in California. The program is designed to get parents to use the appropriate car safety equipment with their children, starting with the first trip home from the hospital. Two main approaches are used. One is an educational campaign to make parents aware of the hazards and importance of using safety belts. The other is an infant car seat exchange, through which safety seats are available to parents in various sizes, so they can get larger and larger seats as their children grow.

To promote awareness, community members in the program have used various techniques, including a contest to find slogans and T-shirt designs; displays at the local library; speaker presentations to local groups like the Soroptimists; car safety booths at a local fair; and fund-raising dinners and benefits. In turn, many local teachers have responded to the campaign by teaching car safety principles to their students.

Once parents are alerted to the dangers, the exchange program makes it easy for them to get the appropriate safety equipment. The Ukiah Valley Association provides safety seats from its stock of about 150, and the borrower pays a minimal $15 deposit when picking it up. There is a $10 refund on return. The remaining funds are used to help finance the program.

But individual communities are not the only ones to express concern. The State and Federal governments have taken some action too. For example, in January, 1978, Tennessee became the first State to pass a law establishing safety requirements for child passengers under four years of age, and subsequently the State launched a Child Passenger Safety Program to publicize the law, and educate residents about the importance of child restraints. Later, Washington State passed a similar law.

On the Federal level, the U. S. Department of Transportation has developed a performance standard for child-passenger protective devices, and has encouraged each State to enact legislation requiring drivers to use devices meeting this standard. Although there is no model law on child restraints, the Department of Transportation has sent copies of the Washington and Tennessee laws to all the States as possible models. The key provisions of both laws is that every parent or individual driving a car should properly secure a child passenger in an adequate restraint system.

Other proposed safety programs are in the offing. For example, the California Chapter of the American Academy of Pediatrics submitted a proposal for a Statewide Child Passenger Safety Program to the California Office of Traffic Safety, in June, 1979. The proposed goal would be to establish a comprehensive, coordinated program to reduce deaths and injuries to child passengers in motor vehicle accidents through increasing the use of safety seats and belts. Among other recommendations, the California Chapter suggests that all obstetricians and pediatricians counsel parents on the need to use a safety restraint with their new baby, inform community members to develop a grassroots organization to promote car safety through contacting local groups, giving workshops, and using the media.

The University of Alabama's Perinatal Infections Clinic Program

In many university affiliated facilities, efforts to deal with preventing mental retardation are multi-pronged. One such Center is at the University of Alabama in Birmingham, where the Center for Developmental Learning Disorders (CDLD), sponsors a Perinatal Infections Clinic. This clinic operates as part of CDLD to identify and care for infants with perinatal infections. Its staff is multidisciplinary and includes three doctors specializing in infectious diseases and the care of children, and several specialists in developmental and learning disorders, who perform developmental examinations and hearing tests.

Perinatal infections can cause serious problems, although they often are unrecognized. According to researchers at the University of Alabama, about 13 percent of all pregnant mothers become infected with certain types of germs that may cause problems for her offsprings—the most common being cytomegalovirus (CMV), rubella virus, herpes simplex virus (HSV), toxoplasma, syphilis, and hepatitis. Not all babies of infected mothers become infected, though it is estimated that approximately one to seven percent of the infants are infected while still in the womb, or during or shortly after birth, and sometimes because of their mother's milk. In turn, about 10 - 20 percent of these infected infants develop serious problems with vision, hearing, or the nervous system due to their infection. A case in point is Ricky, referred to earlier.

Unfortunately, not all of these problems are immediately apparent, a fact which makes diagnosis and treatment more difficult. Only about 10 percent of the infected children are born with symptoms like jaundice, skin rash, pneumonia, microcephaly, seizures, motor disorders, perceptual problems, deafness, and various Central Nervous System (CNS) problems. However, the remaining 90 percent subsequently develop symptoms in the next few years.

Thus, a major function of the clinic is careful monitoring of the infants of mothers who have had infections during pregnancy, so any abnormal or CNS functioning can be quickly detected and treated, possibly by environmental intervention, to improve the child's performance or ability to cope.

Because the effects of damage from infections may not show for several years, the clinic continues its care and testing program through infancy, the preschool years, and even after the child is in school. If abnormalities occur, the clinic staff consults with the parents to devise strategies to help the child develop communication skills, and to find an educational setting that will help the child to develop normally.

PREVENTION RESOURCES

Federal, State and local governmental and private agencies play a special role in assisting or overseeing efforts to prevent mental retardation. These include University Affiliated Facilities (UAFs), Mental Retardation Research Centers, Maternal and Child Health (Bureau of Community Health Services), National Institute of Child Health and Human Development, Division of Developmental Disabilities (Office of Human Development Services), Office of Special Education and Rehabilitation Services (formerly Bureau of Education for the Handicapped), and institutions of higher learning.

The agencies and institutions described here are not intended to cover the universe of resources, but rather to give a brief overview of those agencies, particularly at the Federal level, that provide assistance to State and local governments and private agencies concerned with the prevention of mental retardation.

UAFs Involvement in Prevention Activities

Prevention of mental retardation, and other developmental disorders, is a major goal of PCMR, the Department of Health and Human Services, and numerous other concerned organizations, public and private, throughout the United States. Prevention is also integral to the missions and goals of the University Affiliated Facilities (UAFs), and UAFs, in joint partnership and in leadership roles, have introduced services and other activities that have, and will in the future, significantly reduce the number of individuals faced with lives dramatically altered by mental retardation and other developmental disabilities.

University Affiliated Facilities for the Developmentally Disabled first appeared in Federal legislation in P.L. 88-164, the Mental Retardation Facilities and Community Mental Centers Construction Act of 1963. There are now 47 UAFs located in 34 States. Five satellite centers serve an additional 4 States. UAFs provide interdisciplinary training to medical and other professionals, graduate and undergraduate students, para-professionals, parents, and others. An estimated 77,000 persons were trained in 1979 at UAFs. UAFs disseminate new techniques for the evaluation, diagnosis and treatment of individuals with mental retardation and other developmental disabilities. As an integral part of all these activities, a wide range of services are provided to handicapped individuals - an estimated 46,000 people in 1979.

UAFs, as part of their strong prevention orientation and in support of Maternal and Child Health, Title V goals, have been involved in a wide range of prevention activities. Professionals from UAFs throughout the country have been actively involved in promoting relevant legislation and governmental programs. UAFs have been actively involved with the development, passage and implementation of the Genetics Diseases Act (P.L. 94-278), for instance, through testifying at Congressional hearings, serving on advisory groups, and developing programs to support this as well as other Federal initiatives. UAFs are actively involved on the State level, also, serving on DD Councils, and advisory and administrative boards for a number of programs directly linked to prevention.

Prevention is a regular part of the professional education curriculum at the UAFs. Through on-campus training and off-campus courses, workshops, conferences, newsletters and widely disseminated training materials, professionals in a variety of disciplines are alerted, sensitized, and made more knowledgeable about prevention issues. UAFs are actively involved, through the Prevention and Liaison Committee of the American Association of University Affiliated Programs, the American Association on Mental Deficiency (AAMD) Prevention Committee (2/3 of which consists of UAFs members, including the Committee Chairperson), and joint meetings with the AAMD and Mental Retardation Research Centers, in presenting major symposia on prevention issues which reach numerous professionals each year. UAFs have also sponsored international meetings for social service professionals highlighting early intervention and other aspects of prevention.

UAFs public education programs, through news releases, TV spots, booklets, input to school curricula, and participation in workshops and conferences sponsored by community groups play an important role in prevention of mental retardation. Community outreach has been established as an identified discipline at many UAFs, and serves as an important vehicle for informing, and linking with, the public. UAFs screening activities for such conditions as PKU, lead-base paint poisoning and Tay-Sachs are widely publicized to raise awareness levels and encourage public involvement. UAFs play critical roles in linking parents of high-risk children with vital resources, and in counseling pregnant teenagers, who run a high risk of having mentally retarded or developmentally disabled children. Educating the public on the dangers of fetal alcoholism, and the benefits and uses of amniocentesis, vaccination and immunization are important parts of the UAFs activities.

UAFs are integral to the support and dissemination of research findings relating to prevention. The most accurate and advanced research results are implemented by the UAFs through genetic and metabolic screening programs (involving both testing and counseling, early identification programs, and work relating to environmental hazards).

UAFs have also been involved with industry in the area of product safety to prevent needless disabling accidents, gathering and presenting information on accidents relating to infant cribs, for instance.

As noted by Dr. Allen Crocker, Director of the UAF at the Children's Hospital Medical Center in Boston, "I think it is fair to say that the UAFs are at the crossroads of public, professional and agency activities, and are commonly asked to be spokespersons . . . on prevention." UAFs are not only the spokespeople, but active leaders in providing the services and training vital to the goal of preventing mental retardation, as well as other developmental disabilities.

University Affiliated Facilities have four distinct roles:

1) To train administrative, professional, technical, direct care and other specialized personnel to work with mentally retarded and developmental disabled persons.
2) To demonstrate a full range of exemplary services which should be available to this population.
3) To conduct the necessary research incidental to these activities.
4) To assist the States, regions and communities to reach their respective objectives.

Mental Retardation Research Centers

In 1963, Public Law 88-164 Title I, a Federal act entitled "Construction of Research Centers and Facilities for the Mentally Retarded," led to the establishment of 12 Mental Retardation Research Centers (MRRC) across the Nation.

The primary objective of MRRC is the promotion of more research in the prevention of mental retardation. Mental Retardation Research Centers train research students and fellows in mental retardation and related aspects of human development. All research activities are pertinent to these issues. The philosophy of MRRCs is to integrate basic and applied research. Clinicians, teachers and investigators exchange ideas and data which influence both study and practice in the field of mental retardation. Research results and methodologies are disseminated to other scientists and clinicians via informal exchanges, interdisciplinary seminars and symposia, and publication in professional journals.

The Mental Retardation Research Training Program offers both pre- and post-doctoral training programs in Developmental Biology and Human Genetics, Neurobiochemistry, Neurophysiology, Socio-Behavioral Studies and Infant Studies.

UAF Program Relationship to Mental Retardation Research Centers Established Under Public Law 88-164

By virtue of commonality of interests, legislative origins, and in most instances physical location, the 12 major mental retardation research centers located throughout the Nation should be considered in this examination of research aspects of the UAF program mission. These 12 research centers whose central focus is basic research, receive Federal support from a number of institutes in the National Institutes of Health. However, their core support, administered by the National Institute of Child Health and Human Development, is substantial and has a stabilizing influence.

These multidisciplinary centers were established to address, on a systematic and long-range basis, the many factors that impact upon the condition of mental retardation. They have made substantial contributions in identifying genetic disorders prior to birth, and arresting or reversing some metabolic imbalances leading to mental retardation stemming from social-environmental causes. Several have made major contributions to behavior and educational technology.

Obviously, cooperation and collaboration is desirable between UAFs and research centers. Where both programs are present at the same university, the opportunities for cooperative efforts are much greater. Ten universities have both programs present in a variety of configurations and with little consistency of pattern in their relationships. Of those ten locations, a number include UAFs and research centers as part of the same facility. This physical (and usually administrative) continuity has been highly intrumental and productive in providing good research background for UAF training, while the clinical experience of the UAF has stimulated and focused research activities on problems areas of interest to clinicians.

The differences among these programs are significant. Research activities in UAF's focus (and should increasingly focus) on problems which emerge from the clinical experience of these programs. The research centers, on the other hand, investigate everything from the single cell to complex community intervention programs and sponsor a variety of controlled studies aimed at modifying the physical and social environment of mentally retarded persons. The research centers are involved in basic research not necessarily tied to training-service mission.

For the research centers, interaction with service providers is less direct than in the case of the UAF program. Consumer representatives are less likely to look to research centers for tangible, immediate results or activity than to UAFs with their clinical and community-based programs. Finally, the research centers have retained mental retardation as a focus, while UAFs (at least those supported by the Administration on Developmental Disabilities Office, which, of course, is defined to include certain other conditions in addition to mental retardation) have retained a broader focus.

MCH Prevention Programs and Special Initiatives

The bulk of the $377.3 million appropriated for Maternal and Child Health and Crippled Children's Programs for FY 1980 are allocated to the States on a formula basis for a broad range of health services to mothers, children and the handicapped. These services administered by the States include a number of specific preventive efforts in each State, such as immunization clinics, family planning, maternity and infant care services for high risk pregnancies, school health services, dental care, intensive infant care units, etc. These formula funds are also utilized by the States to support newborn screening programs for metabolic disorders through which 97 percent of all newborns in this country are screened. Support for the management and dietary treatment of over 2000 infants with metabolic disorders and thereby the prevention of mental retardation is also derived from this formula distribution to the States. The bulk of the 160 Child Development Clinics serving over 40,000 children and their families suspected of or with mental retardation, with a major role in the prevention of institutionalization, are also supported by the States through this means.

In addition to the prevention efforts being carried out through the above joint Federal/State programs, the Office of Maternal and Child Health has implemented prevention programs through its research and training programs (including the UAF programs) and the following special prevention initiatives:

- **Immunization Tracking Projects** - designed to develop follow-up systems to insure that all children begin and complete the basic immunization schedule and to identify children who are at risk of not being immunized.
- **National Demonstration Program on Accident Prevention and Injury Control in Children** - a coordinated effort of Title V programs, Emergency Medical Services and Poison Control Centers designed to decrease preventable morbidity and mortality due to accidents in childhood.
- **Improved Pregnancy Outcome Initiative** - Special grants to 33 States with high birth rates, high infant, fetal, neonatal and perinatal death statistics for programs designed to reduce these rates.
- **Improved Child Health Initiatives** - designed to decrease the infant mortality rate in selected areas of States with excessive morbidity and mortality to at least the 1977 level of the State.

Additional programs authorized under the Public Health Service Act and administered by the Office of Maternal and Child Health which include major aspects of prevention efforts are:

The Sudden Infant Death Syndrome Program
The Hemophilia Center Grant Program
The Sickle Cell Education, Testing and Counseling Program
The Genetic Disease Grants Program

THE STATE AGENCIES

State agencies can play a major role in supporting efforts to prevent mental retardation. In 1978 the National Association for Retarded Citizens conducted a survey of State agencies to learn if the State agency provided or financially supported prevention services, what types of services it supported, and whether or not the agency carried out these activities in cooperation with other State and/or local agencies.

Thirty-two State agencies responded to this survey. About two-thirds of them indicated they supported or provided genetic screening, counseling services, and case finding. Following are examples of successful State programs in each category:

States with Comprehensive Statewide Prevention Programs

One of the States with a comprehensive prevention program is California, which has 21 regional centers for the developmentally disabled throughout the State. These centers offer genetic counseling and screening, as well as early intervention services.

Also, California has a High-Risk Infant Follow-Up Program in several counties, including Los Angeles, Orange and San Diego counties, which provides intervention services for high-risk infants. A related program involves early case finding, and there are numerous such programs all over the State. In these programs, the focus is on identifying infants who are at risk of becoming developmentally delayed due to immaturity, physical problems, or age of mother and providing them with follow-up services at home to prevent or reduce developmental delays.

Another State with a comprehensive approach is Florida, which has a master prevention plan, called "Strategies for Prevention of Developmental Disabilities." Each year, the plan is revised and updated by a Prevention Task Force, composed of representatives from various organizations including the State's retardation and mental health agencies, the children's medical services and health programs, the DD Planning Council, the Department of Education, consumers, and others.

Under the auspices of this master plan, a variety of services is carried out. For example, the Florida Department of Health and Rehabilitation Services has 18 different types of prevention programs. Besides assisting the Department with these programs, the State Developmental Services Program Office has four prevention programs of its own. The programs of the two agencies include early intervention services for infants under three, child development training programs for preschools, parent training programs, and a family placement program to prevent disabled children from being institutionalized.

Virginia has a comprehensive prevention program, too, which is carried out by the Virginia Department of Health, and other organizations. Some of the Health Department programs include:

- The Bureau of Crippled Children, which provides indigent children with specialized diagnosis and treatment for a wide range of childhood handicapping conditions.
- The Bureau of Maternal and Child Health, which operates 14 child development clinics that provide a comprehensive pediatric diagnostic evaluation, and offers hospital care to medically indigent newborns, including special treatment for high-risk newborns. Also, the Bureau screens all newborns for PKU and hypothyroidism, and provides family planning services, maternal care to high-risk mothers, genetic testing and counseling, and other services.
- Participation by Virginia's three medical schools,—the Medical College of Virginia, the University of Virginia, and Eastern Virginia Medical School. These offer various services, including a weekly genetics clinic and supporting laboratory services: antenatal testing, using amniocentesis, ultrasonography, and other techniques; and specialty clinics for conditions related to mental retardation, such as problems with metabolism and cystic fibrosis. These schools are also collaborating with the Department of Health to design and deliver a comprehensive genetics screening, counseling education, medical referral, and follow-up program for all of Virginia.

In addition, a variety of public and private organizations, such as the March of Dimes, the Muscular Dystrophy Association, the Community Mental Health and Mental Retardation Service Boards, and the Virginia Association for Retarded Citizens offer a wide range of prevention programs.

States with Statewide Genetic Screening and Counseling Programs

South Carolina and Texas are two examples of States with Statewide genetic screening and counseling programs.

In South Carolina, there are two programs—one coordinated by the Greenwood Genetics Center, and the other, called the "Genetics Associate Program," administered by the Department of Mental Retardation.

The Greenwood Center, founded in 1975, is the major provider of genetic screening services in the State, offering a full range of clinical services for patients and their families, through its main clinic and five satellite clinics. These services include clinical evaluations, counseling, diagnostic laboratory testing, treatment plans, and long-term follow-up, and are designed to prevent the impairments often associated with genetic disease.

The Genetics Associate Program, developed in 1976, was designed to supplement the activities of the center. Through the program, a genetics associate is assigned to each of the four regional genetics centers to review case histories and counsel with families with existing or potential genetic problems.

In Texas, the Genetics Screening/Counseling Service is run by the Texas Department of Mental Health and Mental Retardation. Besides the central office in Denton, there are 13 regional clinics, which provide a variety of services including case finding, referral screening, client scheduling, resources coordination, community education, and follow-up counseling. To assist in the counseling process, a multi-disciplinary team from the central office travels all over the State, and thereafter a team of physicians in the central office reviews the cases to make recommendations on diagnosis and risk counseling.

States with High Risk Intervention Programs

Arkansas and Missouri are two States which have high-risk intervention programs.

In Arkansas, the focus of intervention is on the teenager to decrease the number of adolescent pregnancies and thereby the incidence of developmentally disabled children. The program to do this is a federally-funded, pilot program based in Pine Bluff, Arkansas, called ACCESS, which has been in operation since 1977. It offers a variety of awareness and educational programs to teenagers, parents, and community members, dealing with adolescent pregnancy, the causes of developmental disabilities, nutrition, prenatal care, and parenting.

In Missouri, the Missouri High-Risk Maternity and Child Care Program focuses on the high-risk mother and child. Established by the State Legislature in 1974, the program was developed to reduce the incidence of perinatal mortality and mental retardation by providing medical and surgical assistance to mothers and infants with high-risk conditions. It is administered by the Bureau for the Prevention of Mental Retardation in the State Division of Health, in cooperation with the Division of Mental Retardation and Developmental Disabilities.

Those participating are referred by practicing physicians. To make it possible for any individual to participate, regardless of location or financial means, the program provides funds for transportation to the hospital for care. In addition, the program offers community health nursing in the person's home or in a nearby city or county health department. Besides providing regular nursing services, the nurses inform the individual about supplemental food programs, immunization programs, and other resources for the at-risk infant.

States with Early Casefinding Activities

Several States have programs which offer early casefinding such as Delaware, Idaho, North Carolina, Pennsylvania, and Rhode Island. For example, Delaware has a "Community Nursing and Developmental Program," which serves approximately 900 children and their parents each year. Under the auspices of this program, three nurses and two child development counselors provide four basic services; 1) they go out in the community to locate cases; 2) they intervene early with a home-based self-help program for the developmentally delayed; 3) they refer the delayed to appropriate agencies and consult with these agencies about the case; and 4) they provide up to three months of short-term respite care each year, in which they care for the developmentally delayed child each day in a special center to give the parent a rest from caring for the child. With the exception of respite care, for which parents are charged on a sliding scale based on their ability to pay, all services are free.

In Idaho, Regional Adult and Child Development Centers provide approximately 8,000 children a year with early and periodic screening, diagnosis, and treatment. Once a child is identified as having a developmental disability, he is eligible to receive services at no charge, since financing is provided through the Federal/State Medicaid program.

In North Carolina, multi-disciplinary teams, typically made up of a special educator, speech therapist, a physical therapist, and/or a social worker, make home visits to families with developmentally delayed children from birth through three years of age. Then they work with the parents to enhance their effectiveness as parents, and provide direct developmental training for the child.

In Pennsylvania, the Office of Mental Retardation and the Department of Welfare support 73 projects which provide preschool intervention services for over 3,000 handicapped children from birth to school-age. A similar program is offered in Rhode Island by the Rhode Island Department of Mental Health and Mental Retardation.

Office of Special Education and Rehabilitation Services (formerly The Bureau of Education for the Handicapped)

The Office of Special Education and Rehabilitation Services provides various types of educational assistance including: 1) assisting States, colleges, universities, and other institutions and agencies meet the educational needs of handicapped children requiring special services; 2) administering programs, such as those which offer support for training teachers and other personnel or provide grants for research; 3) providing financial aid to help States initiate, expand, and improve their resources for helping handicapped individuals; and 4) providing media services and captioned films for deaf and developmentally disabled persons.

Prior to the 1979 reorganization of the Department of Health, Education, and Welfare, the Bureau was part of the Office of Education. Since the creation of the Department of Education in 1979, it has been consolidated with the Rehabilitative Services Administration to form the Office of Special Education and Rehabilitation Services. This consolidation occurred to provide a more unified and compehensive Federal policy for education of handicapped people within one Bureau.

PREVIOUS RECOMMENDATIONS ON PREVENTION BY THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION AND OTHER RELEVANT SOURCES

Since 1966, the President's Committee on Mental Retardation has been reporting to the President on the latest strategies to prevent and treat mental retardation. The seriousness of the problem and the importance of the Committee's task is reflected in the fact that over six million Americans today are mentally retarded. It was estimated in a 1977 Report to Congress by the Comptroller General of the United States that an additional four million mentally retarded children would be born by the end of the century, if nothing is done to change the situation.

Given this need to prevent mental retardation and the knowledge of various strategies to prevent it, PCMR has made numerous recommendations about the types of approaches that can be used. These recommendations embrace many different categories, and include: public education, research, health delivery systems, education about environmental hazards, nutrition, immunizations, genetic counseling, family planing, programs for pregnant teens, prenatal care, maternal and child health care, newborn screening for metabolic disorders, caring for premature infants, and early childhood education and intervention.

As the Committee has urged in previous reports:

Public Education

Encourage education for parenthood in your local junior high and high schools.

A national education effort supporting planned pregnancies, which emphasize optimal conception and maternal health, will be one of the most effective means to reduce the incidence of mental retardation.

Using the schools and the mass media as channels for reaching the general public, and professional training programs and journals for reaching those who can influence people's health behavior, the campaign should aim at the most widespread dissemination and application of existing knowledge.

Research

An effective information center should be established at the national level to identify and monitor current research related to the prevention of mental retardation in order to improve the flow of information and its application in service delivery.

The exposure of pregnant women to radiant energy sources, infectious agents, dangerous drugs, and other known and suspected hazards should be minimized until research has clarified the extent of danger these influences pose for the developing fetus.

Continued fetal research is needed to assess the impact of environmental agents which may have toxic effects, or produce congenital deformity or genetic mutation.

Research is needed to improve contraceptive alternatives to reduce unwanted pregnancy and allow optimal planning of reproduction.

Research and demonstration programs are needed to further develop effective strategies for facilitating advancement of young developmentally delayed and mentally retarded children.

Continued and sustained research at basic and applied levels must be supported by appropriate Federal agencies to develop knowledge and implement the best means of early assistance to families and children at risk from psychological and social hazards.

Among critical areas that need study are the role of occupational exposure in producing birth defects and the special problems of women exposed to hazardous substances. (Healthy People, 1979).

Health Delivery Systems

A health delivery system is needed which assures equal access to quality care at reasonable cost.

In addition to the general services which should be provided to all communities, highly specialized services must be provided on a regional outreach basis from university medical centers to community medical programs.

Because intervention at the 0 to three age range is so critical to developmentally disabled children, PCMR urges that either a universal service be established in Title XIX through the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT) or the Right to Education for All Handicapped Act to be amended to include this age group.

Environmental Hazards

More rigorous identification and eradication of toxic substances in the environment, such as lead paint, airborne lead, or waterborne mercury compounds, and specific organic toxic compounds, should be pursued.

Increased leadership, guidance, and efforts by HEW are needed to assure that the incidence of mental retardation (and other adverse effects) caused by lead poisoning is reduced by expanded screening to identify areas having a significant incidence of lead poisoning cases. (Preventing Mental Retardation: More Can Be Done, 1977).

Nutrition

Malnutrition, which is a contributing factor to prematurity, low birth-weight, neurological abnormalities, should be decreased by all means available, including public education on known nutritional hazards, accurate consumer information on nutritional values of processed foods, and by selective supplementary diet for high-risk pregnant and lactating women and their children.

Immunization

Mental retardation caused by rubella and measles can be prevented by aggressive vaccination programs. However, since rubella and measles immunization levels are less than considered necessary, expanded efforts to immunize children and to test women of child-bearing age for susceptibility to rubella are needed. (Preventing Mental Retardation: More Can Be Done, 1977).

Better data are needed on immunity levels in local areas. Certain Federal programs, such as Early Screening (EPSDT), Head Start, and family planning could improve surveillance data and raise immunity levels. (Preventing Mental Retardation: More Can Be Done, 1977).

Genetic Counseling

Genetic diagnostic and counseling services are needed by high risk persons.

PCMR recommends that funding be made available through the Genetic Disease Act for the expansion of amniocentesis testing centers and regional blood testing centers. Title XIX should be amended to establish universal services for testing and treatment.

Mental Retardation can be reduced through genetic screening and counseling, but only a small proportion of those who could benefit from such services appear to be receiving them. Providers of genetic services generally perform little outreach and serve primarily higher income groups. (Preventing Mental Retardation: More Can Be Done, 1977).

Family Planning

The best age for the mother is between 20 and 35; having children when younger or older increases the risk for the child.

Programs for Pregnant Teenagers

Provide the means for States to establish new programs and expand existing programs to resolve the problem of adolsescent pregnancy. The incidence rate of mental retardation in babies born to teenage mothers is considerably higher than the national average.

Prenatal Care

Inadequate prenatal care has been linked to premature and low birth-weights, which are in turn linked to mental retardation. (Preventing Mental Retardation - More Can Be Done, 1977).

Prenatal care that will guard the fetus against damage from maternal kidney infection, diabetes, venereal disease and other hazards should be assured for every pregnant woman from the start of pregnancy.

Maternal and Child Health Care

Comprehensive maternal and child health care services must be available and accessible to all women and their children, including those families with low income and those residing in rural areas.

Newborn Screening

A simple blood test can be used to screen newborns for PKU and congenital hypothyroidism. With dietary manipulation for an infant with PKU, and hormone medication for one with hypothyroidism, mental retardation and other problems that otherwise would develop, can be avoided. (Healthy People, 1979).

Caring for Premature Infants

Intensive care should be immediately available for premature and low birth-weight babies, who are at a greater risk of mental retardation.

Early Childhood Education and Intervention

Corrective measures introduced in early childhood can reduce the severity of the handicap and sometimes reverse its course.

The Committee recommends that the Commuity Service Act be amended to expand the Head Start Program with an emphasis on Home Start.

Community agencies should join forces to deliver programs to "at-risk" and developmentally disabled children during infancy and early childhood.

Access to child development centers for poor and minority group children should be on an equal basis with all families in need of such service.

SUMMARY, CONCLUSIONS AND CHALLENGES FOR THE FUTURE

While economic analyses emphasize the cost-effectiveness of prevention of mental retardation in monetary terms, they tend to overlook or ignore the cogent arguments stressing the social and psychological benefits of prevention activities.

The impressive data on the effects of improved preventive care, particularly to adolescents and medically or socially high-risk groups, is a key starting point. Unwanted pregnancies are clearly high-risk situations. However, the availability of satisfactory care to those who will give birth, to the generation of unborn and to those already born must be among our most important priorities in our national effort to have healthy babies without physical defects and concomitant mental retardation.

The proliferation of neonatal intensive care units has no doubt brought improved care and treatment to the high-risk neonate and premature baby. The positive effects on neonatal survival and improved outcome is a matter of record for the larger low birth-weight babies over 1,500 grams. The outcome for the very low birth-weight survivors is less optimistic, but needs further study. One positive trend is towards the regionalization of care for high-risk mothers and for low birth-weight babies, with varying levels of care within regions.

Genetic counseling efforts are largely viewed as connoting the controversial issue of abortion. Yet the majority of families who receive genetic counseling benefit from the reassurance they receive about a current pregnancy or about the low risks involved in attempting future pregnancies. Again, the social and psychological benefits to the majority are often underemphasized, while cost-effective elimination of an abnormal fetus receives the greatest attention. A strong argument can be made for expanded genetic counseling programs coupled with increased research on the treatment of genetic disorders.

There is no reason why Statewide and regional efforts to implement augmented metabolic screening should not continue and Federal incentives be offered to expand such activities. This must, as has been emphasized, be coupled with satisfactory follow-up procedures and with research on improving screening methodologies and developing better therapeutic approaches, including studies to determine the optimal duration of treatment for metabolic disorders such as PKU.

Expanded immunization programs implemented in the past few years are already paying rich dividends. The prevention of rubella during pregnancy and of encephalitis due to measles are very beneficial demonstrable products of the national immunization effort. It will be most critical to maintain the interest in high immunization levels for the population at large in order to preserve the salutory effects on disease prevention and the resultant decrease in the incidence of sequellae including mental retardation.

The adverse effects of toxins in our environment is a field of burgeoning interest and concern. This report details the harmful effects of alcohol and other agents on the developing fetus and describes the kinds of programs that can be mounted to combat this problem. The harmful effects of significant lead exposure on slum children who ingest old paint and plaster, or to children exposed to lead from contaminated clothing of parents employed in lead related chemical plants, are all well known. The more subtle impact of lower levels of lead exposure are more controversial, though there is evidence suggesting adverse effects in some environmental circumstances. Toxicological research is an area that must be expanded and be associated with improved outreach identification programs.

Another area of importance is the critical role of accidents, including automobile injuries, as a cause of head trauma, brain damage and post-natally acquired mental retardation. Accidents are usually preventable. Consumer education and child passenger safety programs have had beneficial effects in reducing the frequency of serious accidents.

Expanded efforts to promote child safety and prevention of automobile injuries, accidental poisonings and serious falls are needed on national and local levels.

In many communities, outreach efforts to identify preschool handicapped children have only recently begun as a component of "child find" and other endeavors to broaden early education efforts. Yet, there are relatively few high-risk follow-up programs for medically and socially at-risk infants. The technology for early identification is improving, but we need better trained health and allied health professionals to participate in very early identification initiatives. Continued research on the development and behavior of newborns and of young infants is required to assist clinicians to perfect the diagnostic tools required for the early detection of developmental abnormalities. This has become more critical with the realization that early intervention programs have both short and long range positive effects. Few have doubted the substantial impact of such programs on families when parent support, counseling and goal directed intervention strategies are provided to families with a mentally retarded child. The precise effects on the child have been questioned, since unrealistic expectations may have been set for some participants.

The classic example of this phenomenon was the expectation that Head Start programs would produce sustained improvement in early school years, despite the realization that the home and inner-city school environments remained unchanged and apparently did not continue to provide the special attention that the children may have required. Nevertheless, as described in this report, those who maligned or criticized the optimistic goals may have been proven wrong, since long-range benefits have definitely accrued to children who attended Head Start programs.

A wide variety of approaches using structured curricula with varying emphases and components have claimed successes in fostering more normal development and functioning in heterogeneous groups of young retarded infants and toddlers.

Yet, much remains to be learned about the value of various early intervention efforts. When is the optimal timing for these programs? What is the best methodology? How much is the ideal amount of parent participation? Who are the best clinicians/teachers/therapists to be employed and how are they to be trained? How long is treatment required? Are the interdisciplinary or transdisciplinary models the best, and, if not, what approach is best?

Expansion of collaboration by medical and educational professionals to improve diagnostic and treatment methodologies is a requisite for the future. Resources must be provided to make these programs more readily available to all who require them. The declining school-age population, reflecting our national demographic patterns, gives us an insight as to the possibility that current educational expenditures can be rechanneled into early educational and intervention efforts, while enlarged CHAP/EPSDT and Crippled Children's programs could be utilized to expand screening and the critical follow-up care for children at-risk. Mechanisms for reimbursing "non-educational" therapies or so-called "related services" (physical, occupational or speech therapies) will be necessary in order to furnish the important bridge between medical and educational interventions that are necessary to successfully implement coherent programs for children and/or their families.

What is clearly evident is that successful prevention efforts must deal with complex interactions of medical, health, environmental, educational and social factors. Current technology often cannot effectively delineate the exact contribution of each factor or set of factors in producing abnormal development. Therefore, prevention efforts must attempt to achieve a balance in dealing with all potential causative agents or conditions. Broadly based interventions strategies are, therefore, a necessity.

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PCMR RESOLUTION ON PREVENTION

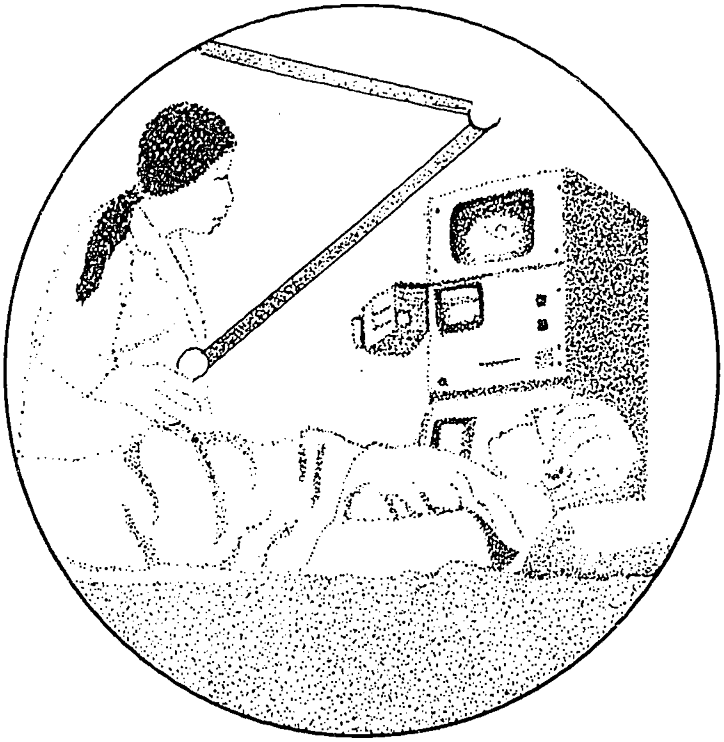
In view of the many preventable conditions and beneficial interventions enumerated in this report and the hopeful outlook that can be fostered by an active and vigorous national prevention effort, PCMR resolves that:

a. Current technology that has proven to be effective in preventing mental retardation be applied in an expanded national prevention effort.

b. Cross-cutting governmental initiatives be instituted to combat and eliminate biological and social/environmental causes of mental retardation. This would require collaboration of aggregates of Federal agencies and combinations of funding streams from the numerous legislative sources and entitlement programs (Title V, Title XIX, Title XX, the Genetic Disease Act, Head Start Programs, Early Education Projects of the Office of Special Education and Rehabilitation Services, Child Health Assurance Programs, Developmental Disability Administration, National Institutes of Health, National Institute for Handicapped Research, Mental Retardation Research Centers, University Affiliated Facilities, Environmental Protection Agency and others).

c. Research be expanded to explore and resolve questions in areas of great importance to biological and environmental prevention efforts, e.g. causes and prevention of prematurity, long-range effects of the expansion of neonatal intensive care units, genetic intervention strategies, the effects of nutrition on prenatal and postnatal development, toxicological and environmental hazards, refining techniques for early diagnosis, evaluation and intervention, short and long-term follow-up of high-risk infants, development of methodologies to understand the nature of the processes that influence cognitive development and which causes dysfunction, factors preventing and stimulating normal social adaptation, and the effects of labeling and stigma on development.

d. In the light of previous PCMR recommendations and earlier Presidential declarations, PCMR wishes to re-emphasize our commitment to the Presidential goal of a 50 percent reduction in mental retardation by the Year 2000 and to urge a major national effort in prevention in order to achieve that goal.



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