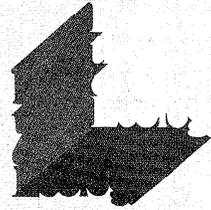
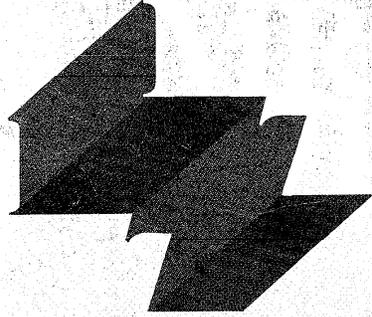


MR 71

Entering the Era of Human Ecology







**The President
The White House
Washington, D. C.**

My dear Mr. President:

It is my privilege to transmit to you the fifth annual report of the President's Committee on Mental Retardation.

This report emphasizes the "new thrust" approach to mental retardation adopted by the Committee during the past year. Based on the concept of human ecology, the approach focuses on the societal conditions in which retardation is bred and thrives.

The report reflects Committee activities of the past year in such specific areas as educational placement, legal rights, lead poisoning, and the special needs of Indian people and of the Pacific region. During the months ahead, the Committee hopes to extend its field of activity to include problems of insurance, screening, the identification and dissemination of models of excellence in facilities and services, joint U.S.-Canadian manpower training, and fuller enlistment of the resources of voluntary and professional organizations, including youth.

The concerned citizens who serve on this Committee believe that by full scale concentration of our knowledge and resources, we can in great measure prevent and modify a condition which now afflicts six million Americans. The problem transects government missions in many areas—housing, nutrition, justice, equal economic opportunity, transportation, in addition to the readily recognized impact of health, education, and welfare. The Committee already has begun to develop a broader working partnership among Federal departments. To make continued forward strides will require the concerted efforts of all levels of government and the tremendous reservoir of the voluntary sector.

We look forward to your continued leadership in mobilizing the Federal agencies and inspiring others who strive at the grass roots level. With these two forces working together, millions of Americans now living and still to be born will have the opportunity to achieve their full potential. The dollar returns will be great, the value in human terms beyond measure.

Faithfully yours,

Elliot L. Richardson
Chairman



Mr. President:

An increased understanding of the factors that shape human development is now emerging as the result of the new thrust of human ecology—man's interaction with his total environment.

The explosion of knowledge in the social and biological sciences as well as the physical sciences has opened our minds to the interrelationship of all aspects of life. The pattern of development for each individual, formed by the warp and woof of his environment and inheritance, is just now becoming discernible. And we are just now becoming capable of changing the pattern.

Since human development occurs in an open system, not a closed, predetermined, static one, it is therefore open to change.

Using what he is endowed with genetically, man is in constant and creative interaction with the forces of his environment, beginning the moment he is conceived. It is this dynamic exchange that determines what each individual becomes, mentally, physically and emotionally.

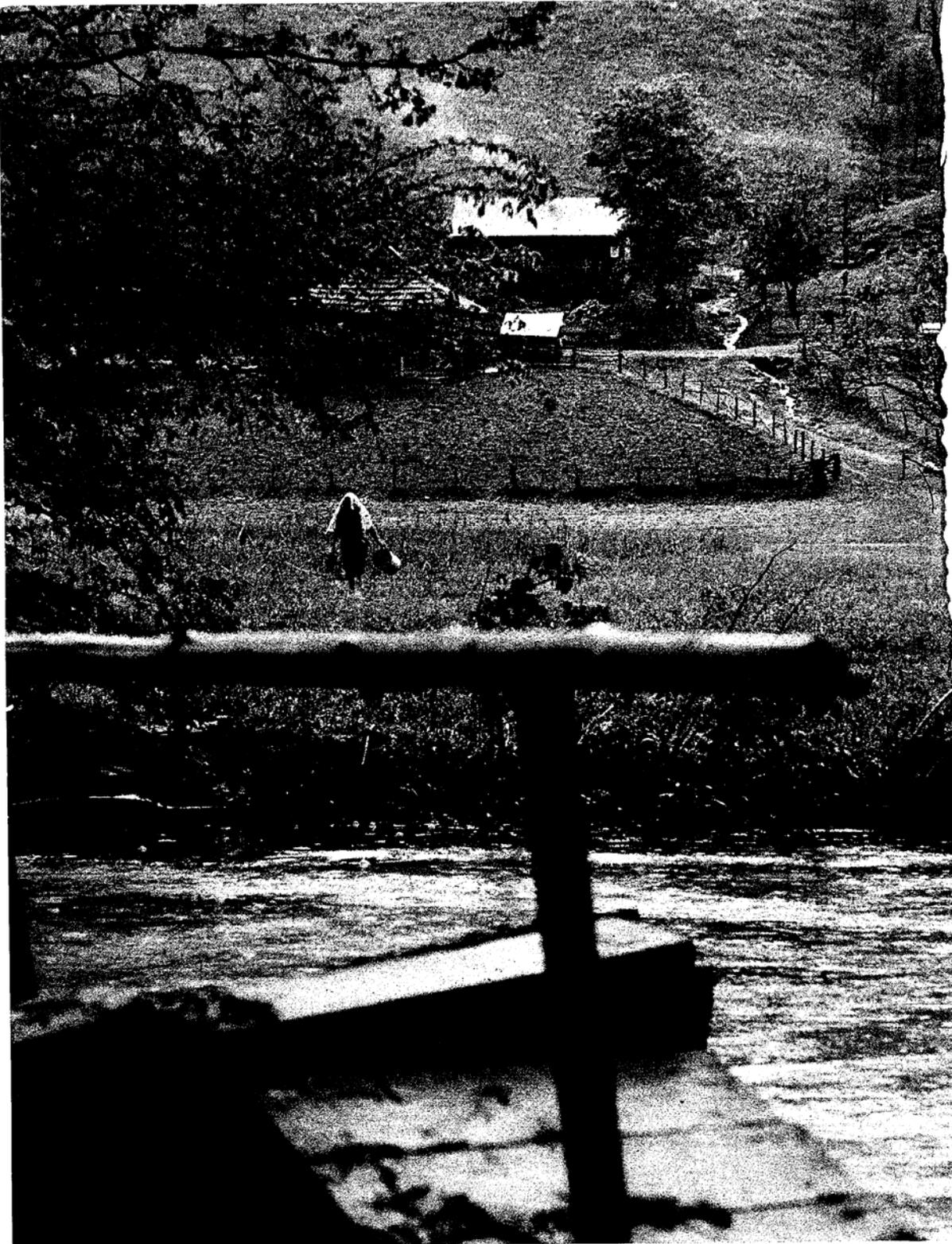
There are few individuals who so reflect both genetic and environmental influences as the over six million mentally

retarded people in the United States. Elements of the environment not only affect their lives, but often are the agents that cause them to be retarded.

If our current and accelerating knowledge of human development were incorporated into all phases of education, health care, city planning, architecture, politics, economics, religion and all other systems that affect the quality of life, our society could then be oriented to the human dimension. The incidence and socio-economic burden of mental retardation would decline significantly; the quality of life for all of society would be uplifted.

Emphasizing human ecology, this report recognizes mental retardation as a part of an interlocking and pathological network of problems weighing heavily on a great mass of humanity.

We have attempted to bring to your attention, and to the attention of the Nation, some significant and recent findings on these matters, with the hope that knowledge can lead to action.



Entering the Era of Human Ecology

It is no coincidence that in isolated rural areas and crowded city slums where the incidence of mental retardation is abnormally high, there is also an unusually high rate of malnutrition, illness, unsanitary conditions, inadequate housing, accidents, lack of health care and education, and the pervading apathy of poverty.

They are all related conditions, with common, interlocking causes. The result is a self-perpetuating cycle.

It is evident that mental retardation is one of the symptoms of these ills of society, as well as one of the causes.

The social system, the economic system, the health system, the education system, the political system, among others, are inexorably linked together also. They are largely responsible for determining the quality of life for everyone, but especially for the mentally retarded who are more

dependent on them than others who have greater control over their own destiny.

The systems, however, are run by people. They, like each individual, are influenced by environment and human capabilities and limitations. They, too, are operating within the framework of the total environment.

In Appalachia, for example, health care and educational opportunity are far below the nation's average. Both would improve if more roads were built to bring the people to the clinics and schools, or to allow mobile units to get to the isolated areas. But the mountains of the region make road building difficult and expensive.

Even if the roads were there, obviously there would still be human problems. One young mountaineer, when complaining about his family's troubles, was asked why he didn't move to the city. He had a car that ran, he lived not far from a paved road, and a

little over 200 miles away was a city where he could possibly find work as an unskilled laborer.

"I'd go," he said, with some embarrassment, "but I can't read the road signs."

His family's living conditions are typical of many families in Appalachia. They get their water for drinking and all other purposes from a nearby creek, which also serves as a disposal for waste matter. Further upstream are some old cars which were disposed of in the only way that seems feasible in such a remote area—dumped on the creek bank. Lead from the batteries can seep into the running water. Mine acid drains into the creek from the unsealed shafts of abandoned mines.

There are five children under eight years of age, and the mother is pregnant. She feels "poorly" but accepts this with resignation, just as she accepts her anemia and the thyroid condition that has affected her health and complicated her pregnancies. Her mother and her mother before her usually felt "poorly," too.

At least two of the children are mentally retarded—one severely retarded. The other three might be called "dull-normal." Since the mother herself never went beyond fourth grade in school, she is not concerned about the children's IQ. What worries her is their dysentery, the constant cough that one of them seems to have—like her husband's—, and the open, unhealing sore that another has on his leg. She also worries about their poverty.

She sees no connection between her husband's sister who is "feeble-minded" and her own retarded children. The possibility of familial defects is as foreign to her as would be genetic counseling.

The family's main food staple is corn—in many different forms—which lacks amino acids essential for healthy development. Thus, protein deficiency, which can be responsible for learning disorders, is another of their

unrecognized problems.

Substitute a cold water flat in East Harlem for the mountain cabin, change the source of lead poisoning to paint flaking off the tenement walls, add air pollution, violence, and the stresses of crowded living, and you find the same problems. Is there any question of the environmental influence on the thinking process—the ability to learn?

Every aspect of a poor environment is a potential threat to healthy human development, mental and physical.

There is evidence to indicate that environmental factors may even alter brain structure and function.

Cornell's Myron Winick and Pedro Rosso of the University of Chile compared the brains of children who had died of malnutrition to the brains of well-nourished children of similar age who had died by accident. They found that the malnourished children's brains consistently had fewer brain cells.

Research suggests that the intelligence of the parent is a vital factor in the intelligence of the children—mainly because of the environment that the parents create for the young child.

Rick Heber, of the University of Wisconsin, found that maternal intelligence was the most reliable single indicator of the level and character of intellectual development in children. The lower the mother's IQ, the greater the possibility of the children scoring low on intelligence tests.

However, Heber and his associates, over a four-year period in a project focused on children of mothers with IQ's under 70, were able to raise the average IQ of their children significantly. (See page 10).

By enriching their environment, he allowed a fuller expression of the genetic potential of these children.

No amount of effort, of course, could make a

genius of a child with an inborn genetic defect or brain malformation. But the achievement of maximum intellectual development requires mental, emotional and physical nourishment at the critical time when the brain is developing most rapidly. That critical time is from conception to age four.

At birth, a baby's brain is about 40 percent

of its adult size, and it doubles its birth size by age two. By the age of three, a child's brain reaches about 80 percent of its adult weight.

Evidence is accumulating that these formative years are the crucial time to act if we are to overcome the deficit that underprivileged children bring to the classroom at age 6.



It is not the genetic endowment but the crushing weight of a hostile environment that either packs its victims down into an apathetic conformity of the lowest order or else results in frantic, sometimes violent attempts to escape.

Improving the environment has the effect of liberating each individual, especially those caught in the poverty trap, to be his own, genetically unique self, capable of then improving the environment which he, in turn, creates.

The *time* when the environmental agent is introduced is vital.

For example, a deprivation of oxygen on the eighth day of pregnancy in mice produces incompletely formed skulls. When the same experiment is done on the 12th fetal day, the result is harelip.

Effective action to encourage development of normal human beings must begin even before conception. Current research emphasizes three approaches:

1. Improving the health of potential mothers prior to conception by increasing health resources and the availability of family planning.
2. Protecting mothers-to-be against hazards during fetal development through more cautious use of medications, decreasing the hazards of environmental contaminants, and more widely applied advances in immunization.
3. Preventing the complications of prematurity—a major cause of infant death and retardation—through prenatal care, nutritional improvement, and more uniform availability of new technology.

Thus, controllable environmental factors—prenatal and postnatal—can be used to encourage the full development of the individual's genetic potential.

These facts are now beginning to be used constructively, as is evident in the rapid expansion of fetal medicine and early

childhood education, developmental day care, and infant programs. Forty percent of the Nation's children aged 3 to 5 are now attending pre-primary educational programs, compared with about 25 percent seven years ago.

The way the baby is handled, rocked, fondled, talked to, sung to, and loved, affects his mental and emotional development from the very beginning.

"Research is accumulating data to indicate that meaningful early sensory-motor experiences can prevent functional mental retardation by the time the child is ready for school," says Columbia's Edmund Gordon. "During the child's early developmental years he passes through significant critical periods when the need to learn is at its optimum. With the passing of certain critical periods, learning then becomes more difficult."

It is at this time, also, when the young child living in poverty begins to be assaulted by an essentially hostile environment that further stunts his capability to develop his innate potential. In his mother's womb he was relatively protected; he is now virtually going it alone.

How is it possible to break into the noxious cycle of hostile environment, genetic errors, and mental retardation perpetuating itself?

Unlike the illiterate mountaineer, some advanced thinkers among the social and biological scientists can read road signs. And signs are now appearing that point in a new direction and give hope for a way out of the wilderness for future generations.

Already there are demands for innovation in colleges of medicine, law, education, theology, architecture and other areas related to the quality of life, whose students are insisting on—and often achieving—curricula focused more on *persons* than on abstract theory.

There is also increasing recognition of the role of ancillary personnel and their potential for improving delivery of services.

The trend is away from the compartmentalized view of specialists, who have tended to divide man into their own specialties, and thus take him apart. The time has come to put him back together again.

Our current comprehension of the interrelated nature of human development makes it mandatory to interrelate the knowledge of divergent specialties and converge that knowledge by applying it constructively throughout the life cycle.

The concept calls for more than reforms within the various disciplines. It calls for the educational restructuring of many disciplines within the biological and social sciences, and bringing them together, so that the center of their *concern* and their *education* and their *practice* is the whole human being living within his environment.

The need for specialists remains pressing, as pressing as the continuing need for treatment. Even more vital to the future of our society, however, is the need to pool the relevant knowledge of the specialists and apply it in preventive ways before the development of such disorders as mental retardation.

The first step toward the achievement of this

goal is the designing of an educational framework based on human ecology to train people to meet biological, behavioral, educational and social needs within the human development timetable throughout the life cycle.

This approach to the understanding of the nature of man and his potential wholeness is an essential academic requirement of this nation.

The President's Committee on Mental Retardation therefore recommends, Mr. President, with a deep sense of urgency:

That the universities be encouraged to develop a comprehensive curriculum and academic program for a new kind of college devoted to human ecology.

That governmental health and environmental services apply and coordinate knowledge of human ecology toward a decisive reduction in mental retardation.

Intelligence

When and *how* and *where* learning takes place can spell the difference between the so-called normal and the so-called mentally retarded child, when there is no physical basis for the retardation.

The effect of an improved environment in the earliest years is currently being demonstrated by the Milwaukee Project, now entering its fifth year.

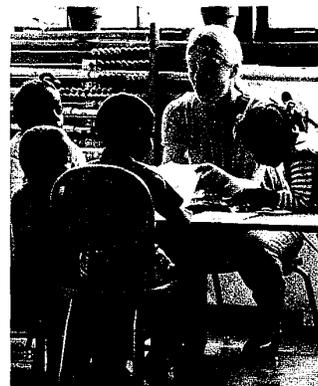
Rick Heber, professor of education and child psychology at the University of Wisconsin, gathered together a human development team including the disciplines of psychology, psychiatry, sociology, speech therapy and education, to study the effects of early childhood stimulation and education on children from the most disadvantaged area of Milwaukee.

Their initial survey of several hundred poor families with newborn babies revealed that the high prevalence of mental retardation in American slums is not randomly distributed or randomly caused. It is concentrated in families with mothers of low intelligence. Mothers with IQ's lower than 80 made up less than half of the total surveyed, yet they accounted for about four-fifths of the children with IQ's under 80.

With the mothers' willing cooperation, the current program of enrichment started. Working with newborn babies of mothers whose IQ is below 70, a staff member of the Infant Education Center visits the home daily for several hours until the child is three or four months old, holding him, talking to him, fondling him and enriching his sensory perception.

At about four months, the child comes to the Center every weekday for a slightly more structured, though highly flexible and individualized program.

By 43 months, the children in the enriched environment are scoring an average of 33 IQ points higher than the control group, with some scoring



to an IQ of 135. Their intellectual development on the average is exceeding the norms generally established by peer groups of the majority culture.

The superior performance is even more noticeable in language development. Children at the Infant Education Center are building an impressive vocabulary by 25 months, some even speaking in sentences. The control group has virtually no vocabulary at that age. A few of the control group children are not speaking at all by 28 months.

Both groups are composed of children who, because of their circumstances, were almost certain to be classified as mentally retarded during their school years.

The new understanding of the learning opportunity in the early years is responsible for the increasing emphasis on quality developmental day-care programs, Head Start, Health Start and the brand new Home Start. All come under HEW's Office of Child Development, which is the Administration's direct and effective response to the now recognized need.

There is also a new look at the validity of intelligence tests.

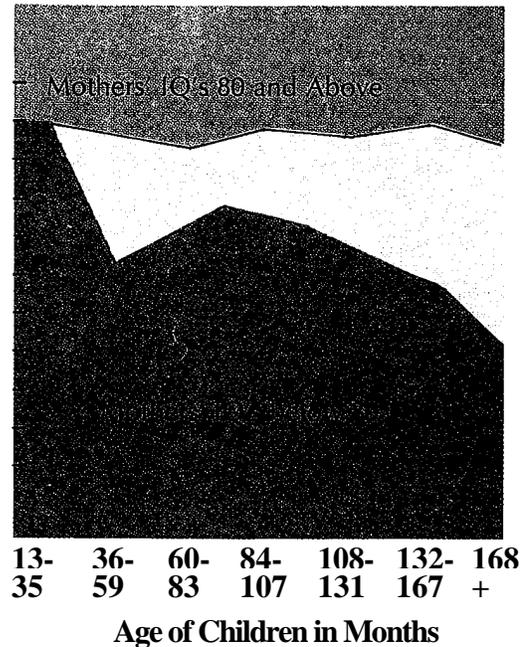
Jane Mercer, a sociologist at the University of California at Riverside, conducted a seven-year study of 1500 children classified as mentally retarded on the basis of their intelligence test scores. She found that the generally lower scores of Mexican-American and Negro children were correlated more with their socio-cultural status than with their ethnic or racial heritage. In other words, they scored low more because they were poor than because they were Mexican-American or Negro.

When the results were adjusted to compare with economic, social, and cultural levels of middle-class white, Mexican-American and

Negro families, the differences in IQ disappeared.

In a nationwide study of 123,000 students, George-

IQ Decrements in Children Whose Mothers Are Retarded

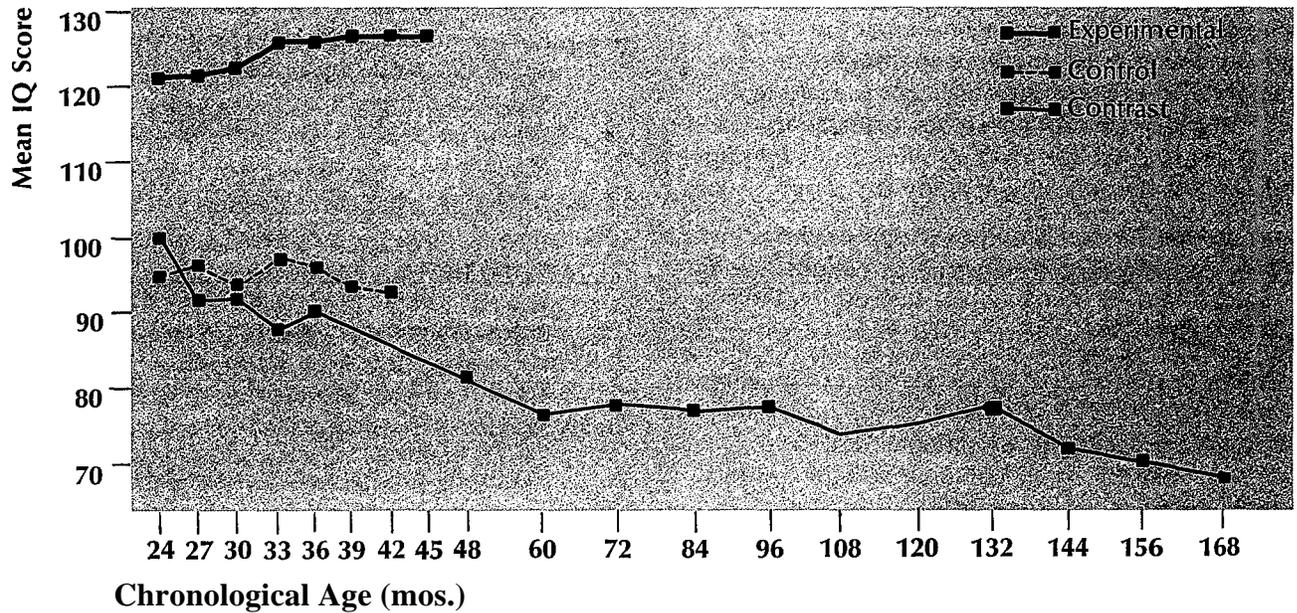


Source:

An Experiment in the Prevention of Cultural-Familial Mental Retardation by Rick Heber, Ph.D., and Howard Garber, Ph.D., University of Wisconsin, Madison.



Experimental, Control, and Contrast Group IQ Scores



Source:

An Experiment in the Prevention of Cultural-Familial Mental Retardation by Rick Heber, Ph.D., and Howard Garber, Ph.D., University of Wisconsin, Madison.

W. Mayeske of the Office of Education, HEW, got virtually the same results: No significant differences in IQ scores between white children and minority group children when social conditions were comparable.

Dr. Mayeske said the original intention of the research was to study the effect of race on test scores. "We ended," he said, "by studying the effect of racism on test scores."

As a result of these clear indications of the effects of a hostile environment on intellectual development, especially in the early years, we recommend, Mr. President:

That developmental day care centers, including educational, health, and nutritional services, be made available to America's children, with priority to those with special needs.



What PCMR Is Doing

Intelligence Tests

In March 1971, PCMR, Bureau of Education for the Handicapped, and The Council for Exceptional Children sponsored a conference on the placement of children in special education programs for the mentally retarded. The conference was particularly concerned with the so-called educable mentally retarded and the "vulnerable" children of the poor of any race or color.

¿Que validez tienen la evaluación, las pruebas, el proceso de ubicación, los medios para situar a los niños? ¿Cuáles son las implicaciones sociales de la ubicación? ¿Cuáles son las implicaciones legales? Estas fueron las preguntas tomadas en consideración.

If you had trouble reading the above paragraph, should you be labeled "mentally retarded"? Here is what it said:

How valid is the evaluation, the testing, the placement process, the use of instruments to place children? What are the social implications of placement? What are the legal implications? These were the questions considered.

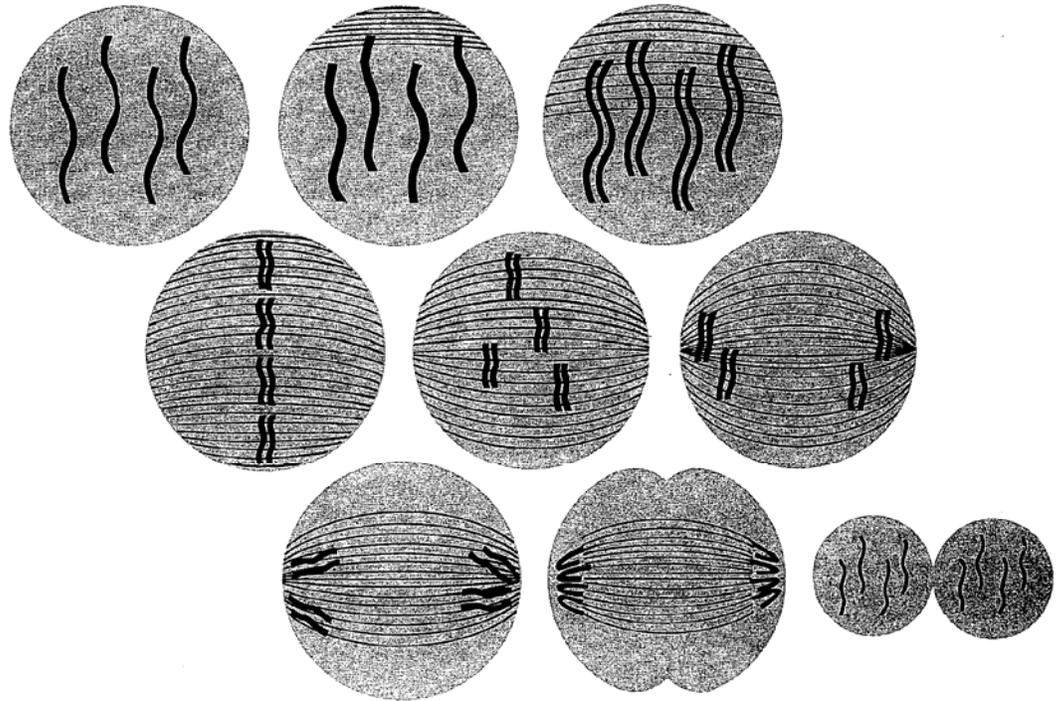
The report of the conference, titled *A Very Special Child*, is available from PCMR.

Following are the conference recommendations:

- 1. Improve and restructure the current testing, placement and evaluation process for identifying children as mentally retarded.**
- 2. Cease labeling children as mentally retarded unless a comprehensive assessment of mental ability, physical health, and adaptive behavior demonstrate a handicap severe enough to justify the designation.**
- 3. Advocate educational justice and freedom for all children through recognition of each child as a unique individual.**
- 4. Sensitize teachers, administrators, school counselors and staff, curriculum developers, and teacher educators to the pervading discrimination against children from social, cultural, ethnic, and economic backgrounds different from the so-called norm.**
- 5. Use the existing legislation, and the Courts, if necessary, to achieve educational justice.**
- 6. Support educational reform through Federal, state and local governmental and private funding.**

In another project, PCMR, the Office of Child Development, the Bureau of Education for the Handicapped, and the Secretary's Committee on Mental Retardation have formed an intergroup committee to produce a manual to assist in achieving successful integration of handicapped children into all varieties of existing and anticipated day care programs.

14



Cell Division

Cell Division

Genetic Damage

A new and blessed event has occurred in medical science—the recognition of the fetus. Scientists are learning his developmental timetable, the processes that keep him alive and that damage him. Some of his problems can now be detected. Others can be eliminated.

About one out of every 600 or 700 children—15,000 per year—is born with Down's Syndrome (Mongolism). Down's Syndrome is a severe genetic error resulting from an extra chromosome.

It is now technologically possible to reduce the incidence of this condition significantly in this decade.

One percent of births in the country now has a chromosomal abnormality that will result in mental retardation or will have some appreciable effect upon the life cycle. A high risk exists in those parents carrying chromosomal defects themselves; those who have had a previous child with Down's Syndrome; those exposed to genetically damaging agents such as virus, repeated x-rays or chemical exposure; or those of advanced maternal age.

At age 25, a woman has a risk of about one in 1,000 of having a child with Down's Syndrome. At age 35, the risk is one in 250. At age 40, the risk is one in 100. And at age 45, the chances rise to at least one out of 50 for that chromosomal abnormality alone. These appear to be conservative estimates.

Genetic counseling is now available in many of the major university medical centers. Before conception, prospective parents can be screened for genetic defects, and counseled on the risks.

This procedure is especially vital if there is a history or indication of genetic defects, mental retardation or developmental problems in either the prospective mother's or father's family.

If this precaution has not been taken, and a woman-at-risk has become pregnant, genetic and metabolic defects can be diagnosed by a study of fluid taken from the mother's amniotic sac. Termed amniocentesis, the technique can detect a variety of chromosomal and metabolic abnormalities which result in severe mental retardation and other disorders. Parents are then counseled on the risks involved and given the opportunity to terminate the pregnancy if the child is found to have defects that cannot be remedied. The optimal safe time for the diagnosis is during the fourth month of pregnancy.

There are now a growing number of physicians trained in genetic counseling and prenatal screening. However, this effort must be expanded to increase the availability of these and other techniques to the nation's population.

Therefore, Mr. President, in order to seize the opportunity to significantly decrease the incidence of Down's Syndrome and other genetic abnormalities within the coming decade, we recommend:

That the opportunity for genetic counseling and amniocentesis for prenatal screening be provided to all high-risk mothers requesting such services.

That research and clinical study of fetal development be increased.

The Law

A Bureau of the Census special report states that in 1969 approximately 450,000 non-institutionalized children, aged six to 15, were not enrolled in school. Many of these were excluded because they are mentally retarded, although the total also includes children who are crippled, emotionally disturbed, or non-English speaking.

Of the 100,000 or more mentally retarded children in Pennsylvania, more than 53,000 are not in public school.

Within recent months, the Courts have changed the situation drastically.

A panel of three Federal judges, ruling on a suit filed by the Pennsylvania Association for Retarded Children, have decreed that all mentally retarded children can benefit from an education and have the constitutional right to education under the equal protection clause of the Constitution. The State must begin teaching such children by next September.

The Pennsylvania decision is the culmination of a series of similar court rulings in Washington, D.C., California and Illinois on the right to education for mentally retarded children. Its impact will be felt across the nation. In Massachusetts, for example, retarded children technically have had the right to be educated in Massachusetts public schools, but in practice, a school superintendent could pass on a child for "custodial care" in a state institution if he felt the schools in his jurisdiction could not provide an education. The Pennsylvania decision is expected to cause changes in such practices.

Already, the Massachusetts Board of Education has taken steps so that evaluation of the child will no longer be made by one psychologist but by a panel composed of a special educator, a physician, a psychologist, and a school nurse or counselor, with parents having the right to appeal the decision.

It will be the responsibility of the panel to

prove why any child should be isolated from his peers and placed in special education classes.

Many interpret such steps in terms of abolishing the label "retarded." Placement will be based on the level at which the child is functioning, with I.Q. measured not merely by tests but by evaluation of his personality, physical condition and achievement record.

The California legislature has enacted into law a procedure for placing children in special education classes which requires that their adaptive behavior be assessed, that the sociocultural characteristics of their family be taken into account and that the parents be involved in the decision making.

A further encouraging note is President Nixon's establishment of the National Center for Child Advocacy to increase public awareness of the social, educational, and emotional needs of children. Pilot demonstration projects have been set up, involving professionals as well as nonprofessionals collaborating on behalf of all children within the neighborhood.

New legislation also is strengthening the rights of the retarded, both as to education and protection against being institutionalized indefinitely without review.

Residents of institutions have, in many cases, remained there until death. Now Massachusetts and New York have incorporated into their statutes the right to advocacy and annual review. In one instance, the thrust of the proposed statute is that the superintendent must annually ask: By what right do I keep this individual in the institution? The burden of proof, by statute, would be shifted from the patient to the superintendent. It then becomes necessary to develop criteria to resolve the question of who shall be retained in the institutions. Annual review establishes a right of the resident, thereby lessening the possibility of one's becoming "lost"

in the institution.

Where a mentally retarded person becomes involved in the criminal process, attention is being focused on his need and right to an advocate at *all* points.

General rights of the mentally retarded which are receiving recognition include:

- (1) The right to training
- (2) The right to medical treatment
- (3) The right to psychiatric treatment
- (4) The right to insurance
- (5) The right not to be experimented upon in institutions
- (6) The right not to be sterilized
- (7) The right to privacy
- (8) The right to marry

The mentally retarded have not gained all of their rights, but the recognition that the mentally retarded have rights is a realization paving the way for the progress that is needed.

What PCMR Is Doing

Law

PCMR co-sponsored a seminar on "Retarded Youth and the Law Enforcement Process" August 18-20 at Salve Regina College, Newport, Rhode Island. It brought together law enforcement professionals and specialists in retardation to discuss such issue as:

How can law officials be helped to recognize a child as retarded early in the law enforcement process?

What are the legal implications in the defense of the youth who is retarded?

What are the implications for juveniles before the courts when retardation is recognized?

Other sponsors were the State of Rhode Island, HEW/SRS, and the Salve Regina College.

PCMR also is planning a national conference on the question of legal rights.

Indian Health and Education

Human ecology has been a way of life for the Indian people since time began.

The earth is our mother. Each grain of desert sand, each singing bird, each bleating lamb, each human being has its place in the nature that makes all things one.

That is the Indian way.

But life within the confines of a reservation falls far short of the Indian concept of what life should be.

Some families have to travel five miles or more for water. Many have no sanitary facilities, no adequate means of heating their homes, no way to refrigerate food, no flooring but the bare earth.

Of the estimated 20,750 families on the Navajo reservation, 19,000 have incomes of less than \$3,000 a year. The average income of all Indians and Alaska Natives is far below the poverty level. Average schooling is eight years.

In a five-year study (1963-1967) of children admitted to the Public Health Service Indian Hospital in Tuba City, Arizona, 616 had a diagnosis of malnutrition; 15 had kwashiorkor; 29 had marasmus. Kwashiorkor is a result of severe malnutrition, and had been seen prior to that time in rare, isolated cases in the United States. Marasmus is also associated with malnutrition. Both occur

before the child reaches age two.

Nearly 15 percent of all pediatric admissions during the five-year study had some form of associated malnutrition. Many had repeated admissions to the hospital.

Often the only milk available to Indian babies after weaning is powdered skim milk. Its supply depends on whether or not skim milk is a surplus commodity from the surplus food program. If this is the sole source of food after weaning, the baby will suffer



from a serious nutritional deficiency.

In some cases, a small amount of evaporated milk has been included in the commodities. But it is usually given to the baby overdiluted and contaminated—either by the only water available or by lack of refrigeration.

The result is malnutrition and repeated bacterial and viral infections. And sometimes death.

While the infant death rate for children under 28 days has dropped dramatically in the last few years due to the efforts of the Indian Health Service, *there are over three times as many deaths of Indian babies aged 28 days to 11 months as the national average.*

Those malnourished children who survive can be seriously damaged in both mental and physical development, since protein and calorie deprivation can stunt the mind as well as the body.

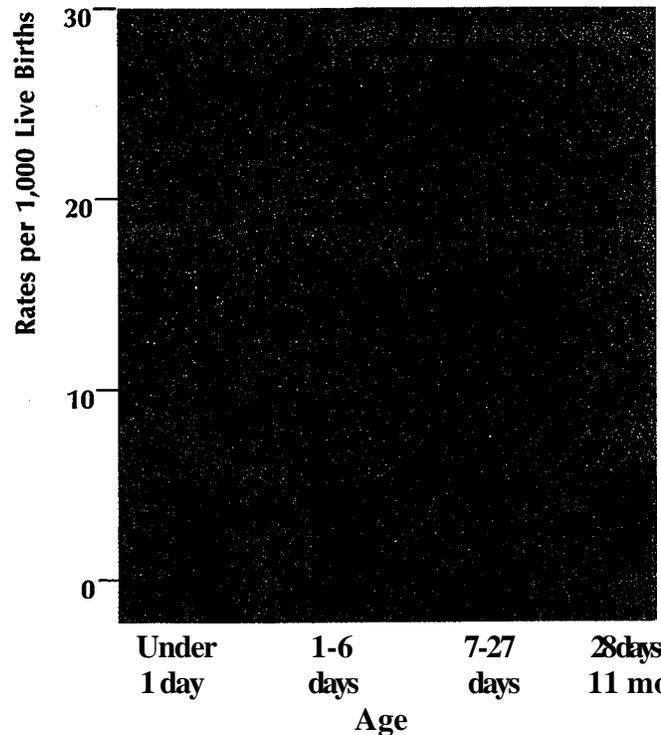
Indian children have further problems when they reach school age. Because their culture and orientation is so different from the culture of the people who design intelligence tests, they frequently score low on the tests. Some are mistakenly labeled mentally retarded. The problem is discussed in the PCMR publication *A Very Special Child*. (See page 13.)

There are still other Indian children who are genuinely retarded and for whom there are few special classes or services.

Mental retardation is not a functional concept in most Indian communities, however. There is great tolerance for "special" members of the community, and a retarded child is not likely to be identified as a problem. He is accepted as another member of the community, who, like all others, has his place in the nature of things.

That is the Indian way.

Infant Death Rates by Age at Death Indian and Alaska Native, and U.S. All Races Calendar Year 1967



Infant Death Rates by Age at Death Indian and Alaska Native, and U.S. All Races Calendar Year 1967

Under 1 day
Indian and Alaska Native ~ 9.0
All Races ~ 9.5

1-6 days
Indian and Alaska Native ~ 5.0
All Races ~ 5.2

7-27 days
Indian and Alaska Native ~ 4.0
All Races ~ 4.2

28 days – 11 mos
Indian and Alaska Native ~ 15.0
All Races ~ 5.0

What PCMR Is Doing

Indian Health and Education

What can be done to prevent the conditions that lead to mental retardation among Indian people, and to alleviate the problems of those now retarded?

In order to answer the question, PCMR has met with key people in the Federal Government with responsibility for Indian programs, and with several Indian groups and individuals. At the invitation of the Indian Inter-tribal Health Board, PCMR representatives attended a three-day meeting in Colorado, followed by meetings with the Southern Ute reservation Tribal Council.

This was followed by an invitation to attend the Albuquerque Area Health Board meeting, in which two Committee members participated. They later visited Acoma Pueblo and took part in a Comprehensive Health Planning meeting.

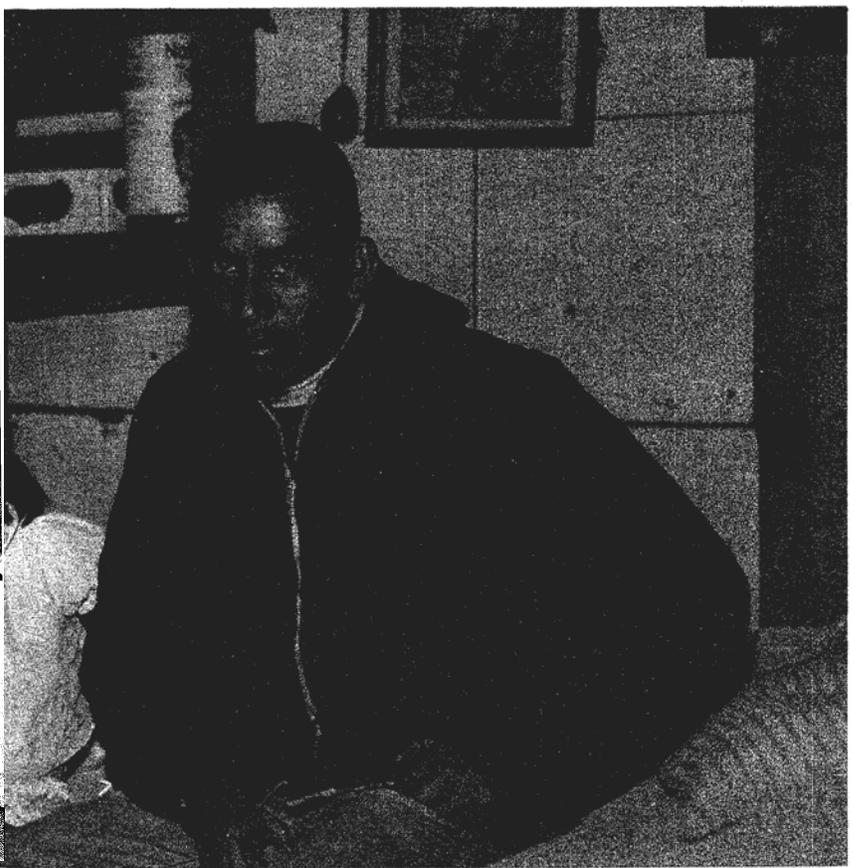
As a result of these discussions, in addition to conferences with Bureau of Indian Affairs and Indian Health

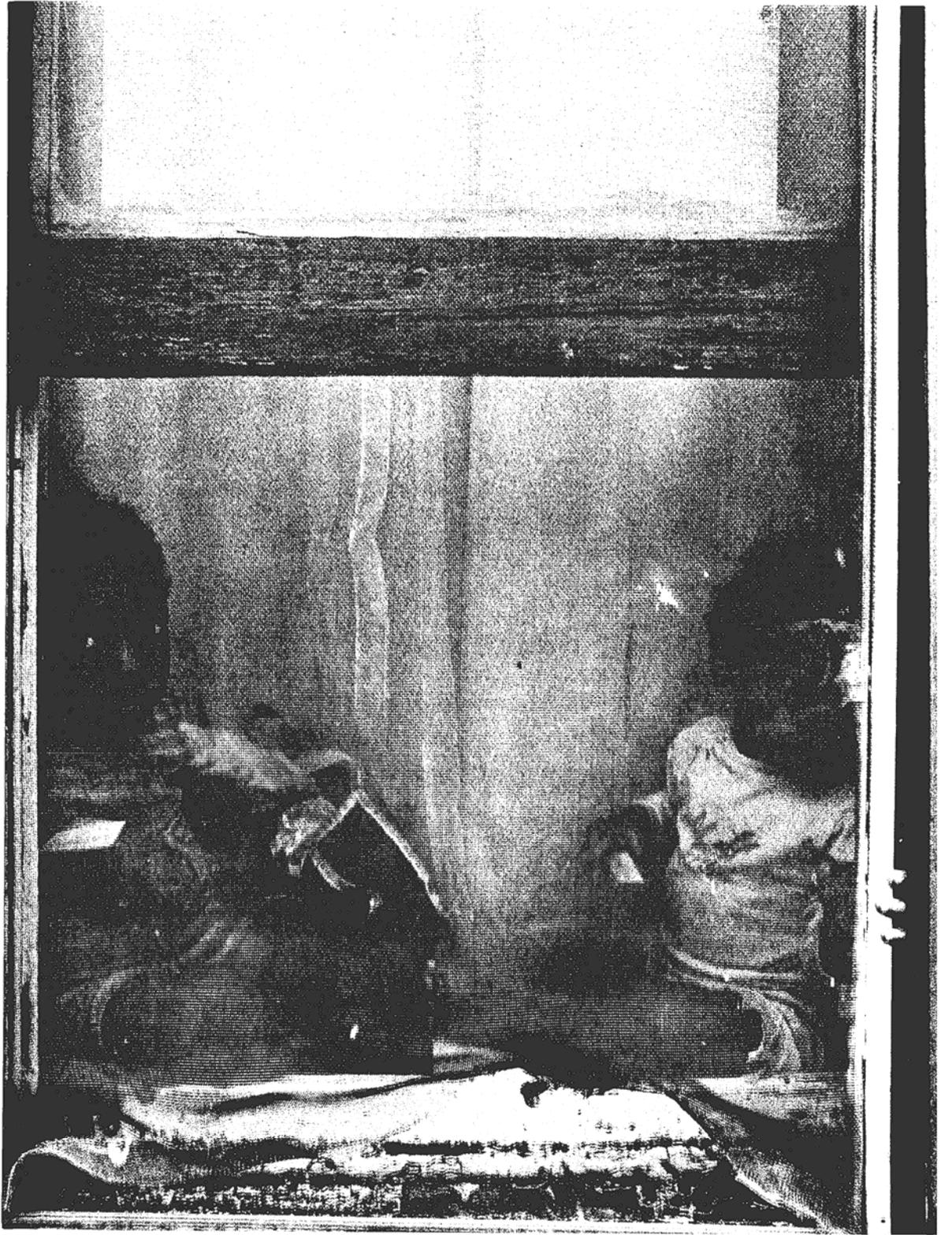
Service headquarters administrators, there are now plans for a joint BIA-IHS Inter-agency Health and Education Council. A series of health education pamphlets on maternal and child health designed and executed by Indian art students will soon be underway. These will go direct to Indian women on reservations, with material appropriate for the differing needs of Indian people in different areas, and suggested for the most part by Indian people in the health and education fields.

Health courses for all students in BIA schools are now in the curriculum planning stage, also with advice from Indian people.

PCMR is acting as "child advocate" in the above projects.

In light of PCMR's experience of the past year, we join with you, Mr. President, in supporting increased involvement of tribal leaders and the Indian people in the planning and management of their programs.





Lead Poisoning

In a follow-up study of 425 children in Chicago who were treated for lead poisoning, 39% had some kind of neurological damage, 54% had recurrent seizures, 38% were mentally retarded, and 13% had cerebral palsy.

It is impossible to say how many children throughout the country have died of lead poisoning, or how many are mentally retarded as a result of it, because the majority of cases are probably never diagnosed. The symptoms resemble those for other illnesses until the final stages, and even then it is often not suspected.

It has been estimated that between 5 and 10% of young children in Boston's slums are now harboring undetected lead poisoning, with no symptoms yet. They are like "walking time bombs," says John W. Graef, chief resident in pediatrics at Children's Hospital Medical Center. An illness or infection could light the fuse and the result could be death or mental retardation.

In some high-risk neighborhoods, screening programs have revealed that as high as 25 percent of the children between one and six have elevated levels of lead in their blood.

Lead poisoning is a completely preventable disease.

It is contacted by young children—usually between the ages of one and three—who eat lead-based paint that flakes off the walls, windowsills and woodwork of old houses.

Legislation in 1940 restricted the use of lead in paint. But as plaster and newer paint peels in slum housing, the layers of the older, lead-based paint come with it. This is what little children have a tendency to eat. Surveys in Baltimore, Philadelphia, and Minneapolis show that from 40 to 80% of the houses in selected slum areas still contain dangerous levels of flaking lead paint applied over 30 years ago.

Many cities, aware of the danger, have started preventive programs, some of which show relatively encouraging results.

The New York City Health Department can now report levels of lead in the blood within 24 hours. Time is of vital importance, since delay in treatment could mean permanent damage or death. In many other cities, it takes weeks to get results from the test.

Programs for finding, diagnosing and treating children with lead poisoning in New York resulted in a decrease in the fatality rate from 27% of detected cases to 1.4%.

In 1963, Chicago launched an intensive case-finding, education and treatment program. By late 1969, over 120,000 children had been tested, and the 1,500 found to be poisoned were treated.

But one-time attempts at detection and treatment cannot be called programs for lead control. Many treated children resume their lead eating habits, others will begin for the first time. What is required is continued screening in known high-risk areas and a continued follow-up of those found to be infected.

There must also be more accurate (and less expensive) testing methods to determine the level of lead in the child's system; more knowledge as to what is an "acceptable" level in anyone, child or adult; and a willingness to undertake a national effort to prevent this largely controllable problem. The latter would have to include renovation of housing in the "lead-belts" of many of the nation's cities.

What PCMR Is Doing

Lead Poisoning

The Committee is formulating a policy statement on lead poisoning to emphasize the Committee's interest in this preventable cause of mental retardation. PCMR is also assisting in the development of pilot projects based in children's hospitals in "lead belts" to clarify the extent and clinical severity of the problem and to seek solutions.



First Pacific Forum on Mental Retardation

With the United States having trust or other governmental responsibility for several islands in the Pacific, and a continuing tradition of interest in the entire Pacific area, PCMR deemed it important to establish a more effective exchange of ideas among the nations concerned. To this end, it organized the First Pacific Forum on Mental Retardation. Delegates from 17 countries convened in Honolulu Sept. 28-Oct. 1, 1971.

In addition to providing the vehicle for a vigorous discussion of practices and problems in the field, the Forum uncovered a desire for follow-up programs of training, assistance, and sharing of knowledge. The delegates expressed five priority needs in a letter that they asked be conveyed to you, Mr. President:

- (1) Assistance in developing further professional and paraprofessional training programs for parents, teachers, and others;**
- (2) Research, the findings to be translated and disseminated;**
- (3) Professional assistance in enlightening the public;**
- (4) Development of exchange leadership programs;**
- (5) Periodic conferences.**

A common theme emerging in many of the papers, responses, and work groups was the impact of urbanization and industrialization on the problems of mental

retardation. Delegates reported a growing need for programs of training and assistance as the complexity of modern life replaces the simple ways in which the retarded more easily found a place.

Exemplifying unmet demands, a representative from Singapore said the five training centers there have a waiting list of 1,474. Among the many needs identified were training courses to develop more teachers for the retarded; short courses on genetic services for public health workers and private practitioners; international sharing of experience in controlling infectious diseases; supplementing diets of women of child-bearing age, and carrying out a planned population policy. Mass screening of a simplified type and expansion of services for the preschool child also were proposed.

As one outgrowth of the Forum, the American Association on Mental Deficiency has arranged to make literature in the field available to Pacific nations.



What PCMR Is Doing

International

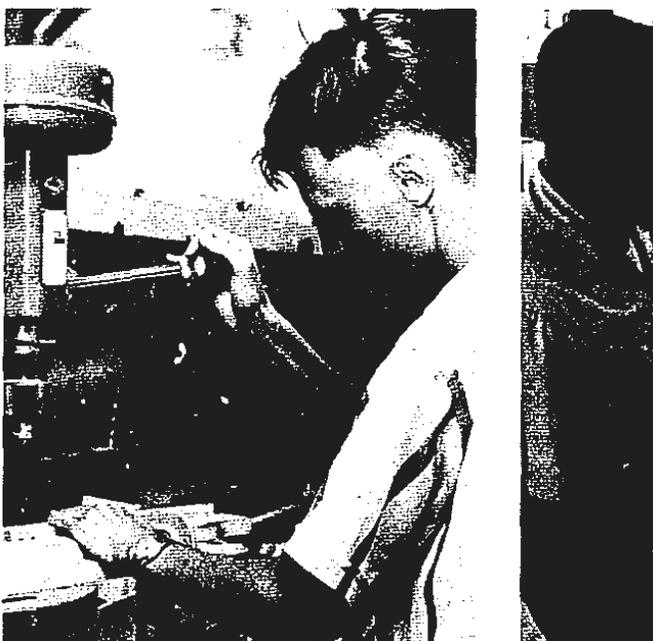
PCMR and the National Association for Retarded Children cosponsored an International Symposium on Volunteers for the International League of Societies for the Mentally Handicapped, held in Pennsylvania. Topics included training volunteers; the youth volunteers; the volunteers and the professional; and related subjects. Participants came from Belgium, Brazil, Canada, Chile, Colombia, England, France, Germany, Sweden, Switzerland and the United States.

The Committee has further expanded its international activities by forming a U.S.-Canadian study group on manpower, with the hopes of developing a model program.

Following a Caribbean conference on mental retardation, attended by PCMR representatives, there has been a continuing effort to coordinate and exchange information on services and programs.

PCMR was represented at an international conference on special education held in Sweden, and attended by delegates from 24 countries. The meeting was followed by site visits to facilities in Denmark, France and England.

PCMR also participated in a European conference on vocational training and rehabilitation, sponsored by the International Labor Organization. The World Health Organization has utilized the experience of several Committee members to broaden the understanding of how the quality of life can be improved through health education.



Economics

(From a study on the *Economics of Mental Retardation*, commissioned by PCMR.)

An estimated 5.4 million persons in the United States under 65 years of age have IQ's below 70, about three percent of the population.

Children of the poor are about ten times more likely to be retarded than children of the middle and upper classes.

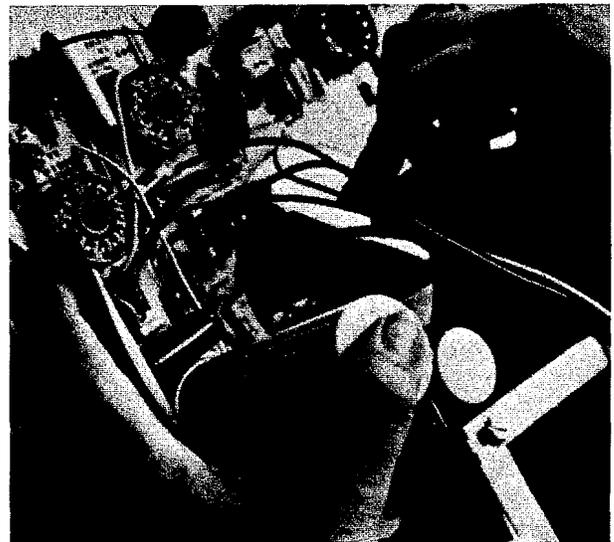
If the children of all population groups had the same rate of mental retardation as those of middle and upper class whites, the prevalence of retardation would decrease by 80 percent.

A partial estimate of the *social cost* of mental retardation in 1968 was \$5.6 billion. This includes the loss of productivity due to mental retardation and the "excess" cost of service provided to the retarded—i.e., those costs that are greater than would be incurred for non-retarded persons. For example, the "excess cost" of special education is the difference between regular educational costs and special educational costs. Of this \$5.6 billion, about \$2.4 billion was paid by taxpayers in the form of increased taxes to provide services to the retarded or to compensate for the increased taxes that would be paid by retarded people if they had the same earning level as the general population.

The vocational success of the mentally retarded is better than is generally believed. An estimated 87 percent of mildly retarded adult males (IQ 50-69) are employed, a rate that is only four percentage points below that of males in the general population. Among mildly retarded women, the comparable rate was 33 percent. Although this rate is 12 percentage points below that of women in the general population, much of the difference is explainable by the greater tendency of mildly retarded females to be fulltime homemakers.

In both cases, earnings were slightly over 85 percent of average wages in the population.

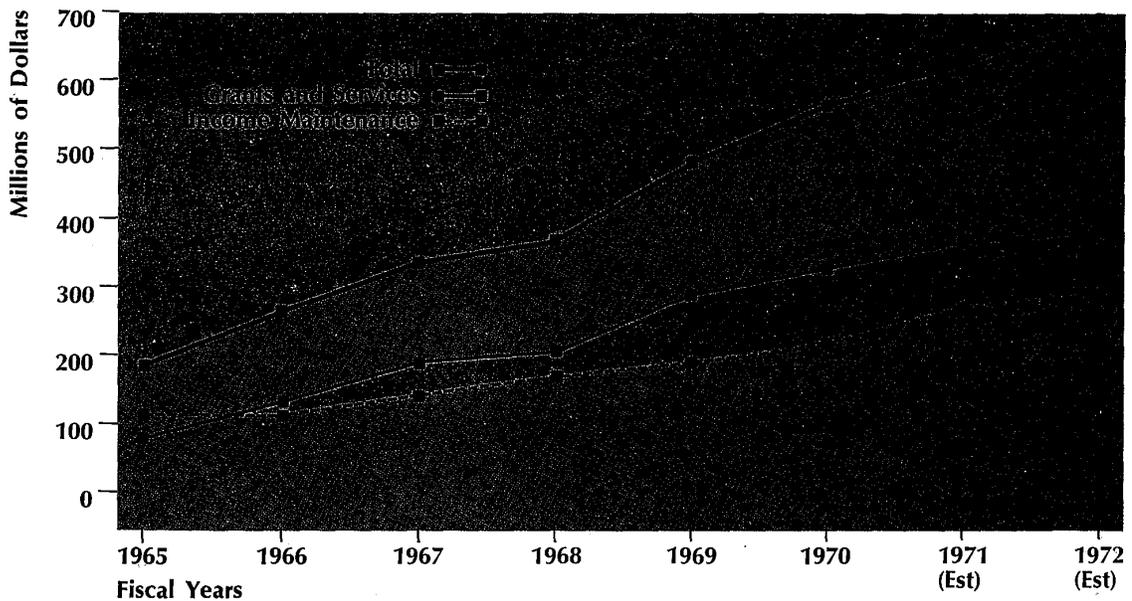
The mildly retarded constitute the great majority of



the mentally retarded. In most cases, mental retardation is not a barrier to work. Even among persons with the IQ's between 40 and 50, an estimated 45 percent of males and 12 percent of females are employed at wages that are 19 percent of the average in the population. The retarded who do not work are usually persons with IQ's below 50 and those who are multiply handicapped.

The lifetime earning of a retarded worker are high. A mildly retarded male who entered the work force at age 18 in 1968 could expect lifetime earnings of over half a million dollars, assuming a 2.5 percent annual growth rate and expressed in terms of 1968 prices. He can earn five to nine times what it costs to train him for employment and community living. In addition, by working, he reduces the rate of institutionalization.

Obligations for Mental Retardation Programs
 Department of Health, Education, and Welfare
 Fiscal Years 1965-1972



Recreation

The inclusion of a wide choice of physical activities, individual games, cultural events, hobbies, environmental education and outdoor recreation opportunities in the total life span of the mentally retarded individual is necessary for total humanization. The recreation dimension of an individual's life needs to be formulated throughout the entire life span and especially in the early childhood years to gain some degree of leisure independence.

The mentally retarded individual is being provided services by municipal recreation agencies in over 50% of our nation's cities with a population of over 100,000 according to recent projections.

Along with these municipal recreation programs are several thousand camps (residential and day), and one-day-a-week programs, being sponsored by local, public and volunteer organizations, as well as the vital recreation component within residential facilities.

Major efforts by such national organizations as the American Association on Health, Physical Education and Recreation; Programs for the Handicapped; the National Therapeutic Recreation Society of the National Recreation and Park Association; The Joseph P. Kennedy Jr. Foundation; the National Association for Retarded Children, and the American Association on Mental Deficiency's Recreation Subdivision have highlighted the broad national involvement in recreation services.

What PCMR Is Doing

Recreation

In several meetings sponsored by PCMR, The President's Council on Fitness and Sports and the Bureau of Education for the Handicapped, there has been an attempt to explore some of the dimensions of recreation and physical education for the mentally retarded.



PCMR Projects in Preparation

A list of exemplary community-level programs for the mentally retarded throughout the United States.

A report on practical implications and application of the welfare program in providing benefits and services to the retarded.

A bibliography of books, publications and brochures that best describe mental retardation.

A study of transportation systems in order to aid the retarded in reaching services. Recommendations will be made for improving transportation services.

A national survey of voluntary, lay and professional groups to determine innovative programs for children with birth defects.

Development of a method for collecting data on services delivery systems to the mentally retarded from 50 States and D.C.

A conference on comprehensive screening for all pre-school children.

A monograph on citizen advocacy leadership training.

Support of the section on mentally retarded children at Citizens' Conference on Priorities and Action for Children and Youth.

Examination of administrative and program components of adult activity centers and state and local laws and regulations applicable to their operation.

Fostering implementation of recommendations concerning training and employment of the retarded made in joint PCMR-President's Committee on Employment of the Handicapped publication, "These Too, Must Be Equal."

Regional Staff Development conferences planned jointly with HEW regional offices.

Goals of PCMR's New Thrust

Using present knowledge and techniques from the biomedical and behavioral sciences, it is possible:

To reduce the occurrence of mental retardation by 50 percent before the end of this century.*

To largely eliminate Down's syndrome (Mongolism) within the next two generations.

To avoid the disastrous effects of rubella and other viral infections, by inoculation, vaccination, and other preventive measures.

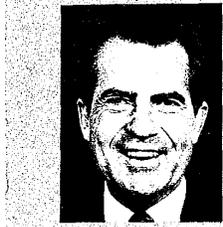
To undo the harm done thousands of children wrongly identified as retarded by faulty tests.

To prevent the retardation that would occur because of social neglect and public disinterest in great segments of minority groups.

To permit conception and birth of normal, healthy infants through genetic counseling of parents-to-be and prenatal care of the mother.

To return one-third of the retarded now living in institutions to community living, and make them into useful citizens through training for productive employment.*

** Since this report was written, President Nixon has declared these to be "major national goals."*



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**The President's Committee on
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