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## MEDICINE

## Retardation: Hope and Frustration

FROM the moment Tracy was born, Arthur and Claudia Albertsen of Chicago knew something was wrong. The doctor kept saying that delivery had been normal; nurses, who usually bustle cheerfully around a new mother, were strangely silent. Says the mother now: "Tracy came into the world not fully completed. She is literally missing part of her brain." The victim of a chromosomal abnormality, Tracy suffers from what doctors call "profound" mental retardation. At 21 months, she can neither walk nor feed herself, nor say the few words that most children her age have begun to utter. Her life expectancy is short.

For James and Clara Leonard of Sacramento, Calif., the crushing news was years in coming. Their son, Jimmy, now 15, seemed normal at birth, but then developed slowly. When he entered kindergarten, teachers urged the Leonards to take Jimmy and his younger brother, who was showing the same signs of mental dullness, to a hospital for evaluation. Doctors who examined the boys could find no sure cause for their condition. They had no doubts, however, about the diagnosis: both are "moderately" retarded and in need of long-term special training.

Tracy Albertsen and the Leonard boys represent two of the faces of mental retardation. Children like Tracy owe their affliction to detectable organic imperfections: those like the Leonards suffer from retardation of uncertain origin. Together they constitute a wrenching problem for all segments of society. According to the President's Committee on Mental Retardation, 3% of the population under the age of 65—close to 6,000,000 Americans—suffer some degree of retardation. Every five minutes in the U.S. a child is born who will eventually be classified as retarded.

**Social Price.** The impact is enormous, scarring both individuals and their families. Nor does it spare the country's image of itself as an enlightened society. The total annual cost in the U.S. for the care and education of the mentally retarded comes to more than \$6 billion, a figure that is both large and inadequate. The social price is even higher. Because society has provided few alternatives, some 200,000 victims pass their lives in institutions that for the most part are unfit for humans. Many of the rest exist in a twilight world that they can understand dimly, if at all, casualties of indifference and lost opportunities.

Perhaps the cruelest fact of retardation is that many cases could be prevented or significantly helped with the application of present knowledge. The past decade has witnessed the beginning

of a revolution in this field. Public attitudes toward retardation have never been more understanding, thanks largely to the efforts of the parents of the retarded to bring the problem out of the closet, and the support of the late John Kennedy. He and his family gave the cause respectability by publicly acknowledging that his sister Rosemary, now 53, is retarded. J.F.K. also pushed through legislation for research and training in the field. Scientific advances in diagnosis, treatment and prevention have kept pace with evolving social attitudes. Dr. John O'Brien, head of the department of neurosciences at the University of California in San Diego, believes that "we may have seen more answers in recent years in this field than in any other in medicine."

This explosion of knowledge has yet to produce much practical fallout for the majority of today's retardation victims, or for those who will soon be born. While diagnostic techniques have improved, making earlier recognition possible more often, inadequate medical

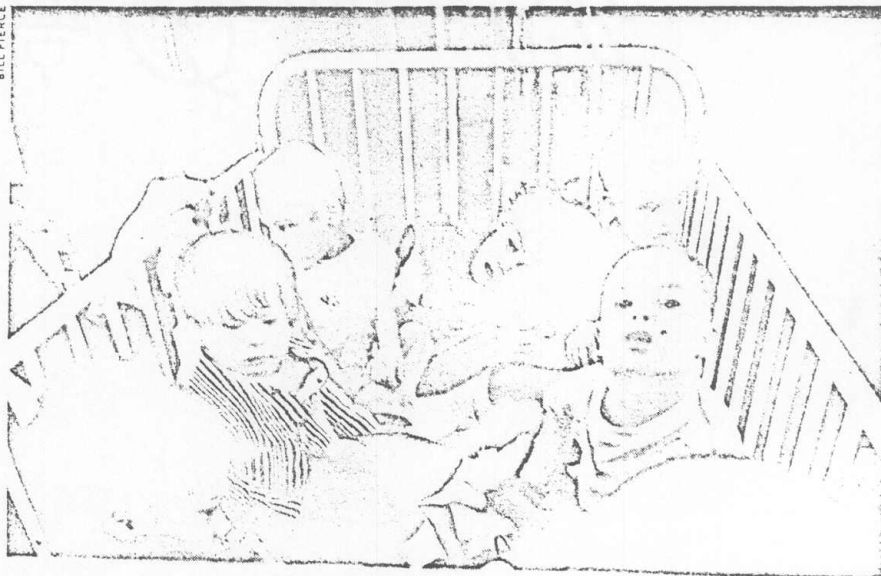
and educational services still prevent many children from getting expert help soon enough to make a difference. Though more physicians, educators and psychologists have become interested in the subject recently, many who were trained years ago are still unskilled in dealing with the child and counseling his parents. The development of antibiotics and the rapid improvement in procedures that save the lives of sick infants, meanwhile, have allowed more of the retarded to survive childhood. Thus their number is likely to increase, at least for the short term.

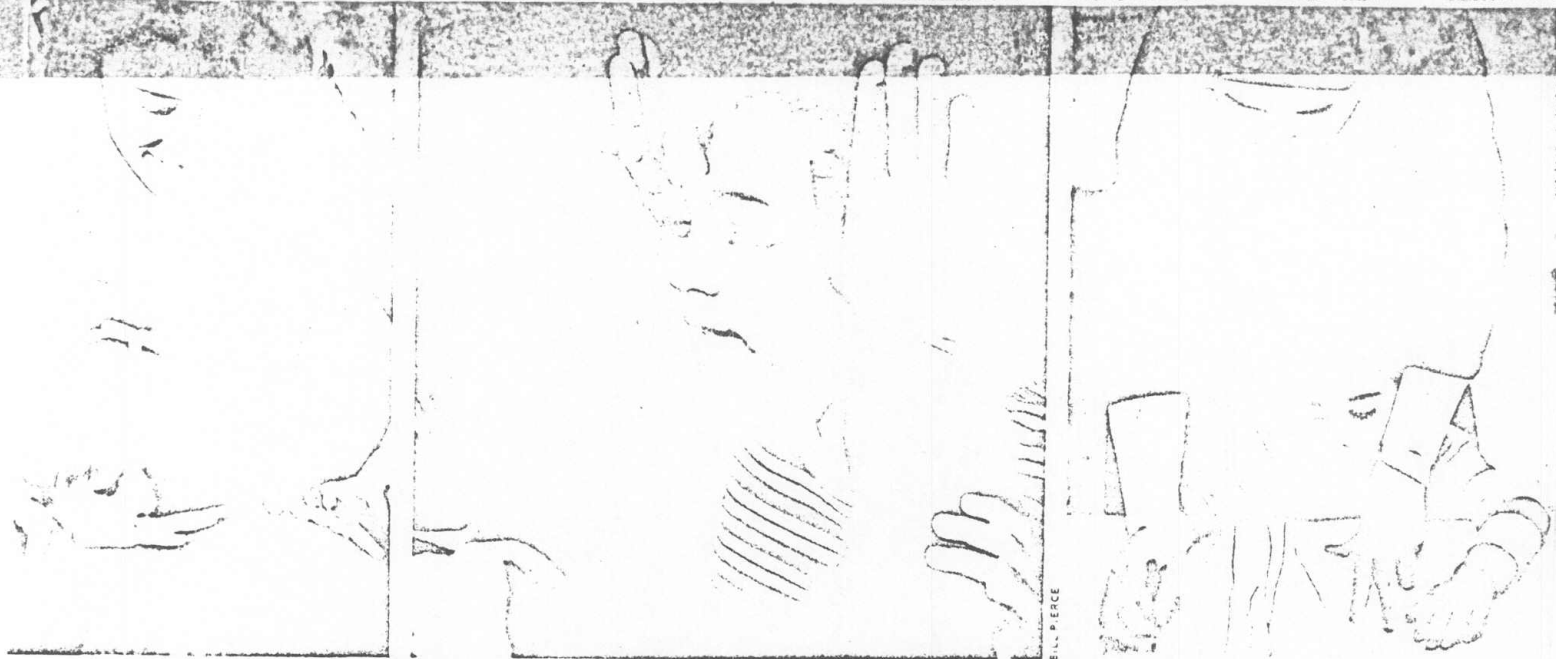
**Cultural Causes.** Though there are more than 200 known causes, the disability can be divided into two broad but somewhat arbitrary categories.

The first group consists mainly of people rated as severely or profoundly retarded—those with IQs ranging from 30 down. Usually these people, like Tracy Albertsen, have clearly detectable physical flaws. Some suffer from chromosomal abnormalities, such as Down's syndrome, or mongolism. Others have genetic problems such as phenylketonuria (PKU), a condition caused by lack of an essential enzyme. Still others acquire congenital infections like syphilis or are affected by German measles contracted by the mother.

The second group is made up most-

CHILDREN EN ROUTE TO THERAPY AT WILLOWBROOK





PLAY THERAPY WITH BALL, SPONTANEOUS COMMUNICATION AND DRAWING LESSON AT NEW YORK'S KENNEDY CENTER  
 Welcome progress in the long search for antidotes to poverty's poisonous effects on the mind.

ly of those called moderately and mildly retarded, with IQs of between 30 and 75. They are for the most part medical mysteries, like the Leonard brothers, who appear to have no physical defects. Some have suffered birth injuries that produce slight brain damage, the effects of which appear years later. Most seem to be casualties of their environment, starting with the womb, their disabilities the result of a congeries of medical, cultural and economic causes.

**Cat's Cry.** Science at present understands the more serious forms of retardation better than the less serious ones. Chromosomal problems like mongolism or *cri-du-chat* (cat's cry) syndrome, which leaves an infant with a partially developed head and brain and a peculiar mewing voice, can be spotted almost immediately after birth.

None of these severe conditions can yet be cured. But as a result of recent scientific developments, many can be prevented. German measles, responsible for the birth of many retarded infants, has been nearly eliminated thanks to a nationwide immunization campaign. PKU's effects can be checked by a special diet if the defect is immediately identified; 43 states now require a PKU test at birth. Doctors can recognize the chromosomal flaw that causes mongolism and 27 of the genetic quirks known to cause retardation. More important, they can diagnose these in the fetus by amniocentesis. A needle is inserted into the uterus to draw off a sample of the fluid in which the fetus floats. The material is analyzed for extra or missing chromosomes or absent enzymes.

The procedure has been performed on thousands of women so far and is regarded as safe and effective. If it reveals a flaw early enough in pregnancy, the parents then have the option of abortion. Amniocentesis is elaborate and expensive. However, it should be considered whenever there is an unusu-

ally high risk of retardation or other disability. For instance, women over 35 are four times as likely to have mongoloid children as younger mothers. If all older pregnant women were tested and would agree to abortion where warranted the incidence of mongolism could be cut in half. If genetic counseling becomes a widespread practice and related medical services become generally available, retardation resulting from other known, hereditary causes could be sharply reduced.

That kind of defect, however, accounts for only about 20% of the retarded in the U.S. For the other 80%, who are functionally rather than physically retarded, physicians can rarely find precise causes. A growing number of experts believe that this nonspecific, generally milder form of retardation, the primary symptom of which is poor intellectual performance, is a socioeconomic disease. While genetic, chromosomal and hereditary causes occur with about the same frequency in all racial and economic groups, retardation of unknown origin is nearly ten times more likely to occur among the poor, black and Spanish-speaking in the U.S. than among the white and affluent.

The reasons are not racial, according to Dr. Robert Cooke, chief of pediatrics at Johns Hopkins Medical Center in Baltimore. Says Cooke: "Intelligence is controlled by so many genes that it would be biologically impossible to allocate an aggregation of these by race. Since the genetic pattern is essentially the same for all races, we must assume that any differences in intelligence are environmental."

The poor tend to be less healthy and get less prenatal care. An estimated 30% of America's expectant mothers get no medical attention at all, and these are nearly all daughters of poverty. Their children are more likely to be born prematurely, to contract serious

diseases during infancy and to suffer from malnutrition during the first three years of life, when 80% of all brain growth takes place. Doctors and educators agree that language, words as a key to handling ideas, is the *sine qua non* of intelligence. Yet the children of the poor, white or black, are less likely than middle-class youngsters to get the intellectual stimulation essential to their mental development. Some parents in urban and rural ghettos still follow what Mrs. Mary Robinson, director of Baltimore's Martin Luther King Center for Parents and Children, calls a "slave tradition" in child rearing, which inhibits the development of language ability. "We teach our kids to be quiet and not to bother us and not to bother everyone else," says Mrs. Robinson. "We had to do this in order to survive, but we don't have to do it any more. It's killing us."

**Bedlam Approach.** Because most environmentally retarded children develop physically at a normal rate, parents often fail to realize that the youngsters' minds are not keeping pace. Compensatory programs must be started early if they are to be effective. But most children of this type are not diagnosed until they have entered school, and many schools are inadequately equipped to deal with them. As a result, the child not only fails to catch up, but is likely to fall further and further behind those of his age. If he becomes mentally disturbed as well, he may be put in an institution. More likely, he will simply drop out of school to enter a labor market that has fewer and fewer jobs for the unskilled.

Whatever the cause and whenever it is made, a diagnosis of retardation can be a preface to tragedy. Nervous breakdowns, divorce, suicide and even homicidal tendencies are believed to be more common among the parents of the retarded than in families without the



problem. Many parents predictably blame—and pity—themselves. One of the most difficult decisions is whether to keep the child or have him "put away." For some, an institution is the only answer; the burdens of home care are simply too great, the impact on the family too disruptive. Others, to whom that prospect is intolerable, frequently find good alternative care unavailable.

Most parents and specialists now realize that the typical large state-run custodial institution must be regarded as the very last resort. Even in states that have relatively progressive policies toward the treatment of retardation, such facilities are Hogarthian reflections of a Bedlam approach to the problem. They are chronically short of funds and personnel, do little to train the more seriously afflicted and can rarely maintain even minimal standards of hygiene. One

STEVE HANSEN



WORKSHOP AT HATHORNE SCHOOL  
A right to education.

example is New York's Willowbrook State School on Staten Island, where a cutback in state appropriations recently caused conditions to deteriorate to the crisis point (TIME, Feb. 14). Talking about the care in state custodial institutions generally, Willowbrook Director Jack Hammond says: "It's inhuman. We're treating the mentally retarded as if they have somehow offended society."

There is now a consensus that the concept symbolized by the Willowbrook of the U.S. has failed on all counts, that even if more funds were available for them, they would merely become slightly less dismal warehouses for society's rejects. Nor are private institutions a feasible alternative for the vast majority of families; fees run from \$3,600 to \$8,000 a year. Most experts have concluded that all but the most seriously afflicted are best served by normal surroundings. This means living at home and having access to training

and treatment, or living in small residences where close, personal attention is provided.

Such an approach requires large amounts of money and expertise, and some states have begun to supply both. In 1966 Massachusetts passed the Community Mental Health Act, which set up regional boards to evaluate needs and plan facilities. Says Dr. Milton Greenblatt, the state's commissioner of mental health: "We're trying to phase down the institutions and close the snake pits." One large facility has been closed while the patient load at others has been reduced. The Hathorne State School, a new center serving a region with a population of 900,000, provides in- and outpatient services, day care and community residences.

**Name Game.** Nebraska, Georgia and Illinois have built community facilities where the retarded who continue to live at home can be helped. No other state has gone as far as California, which in 1971 created a network of comprehensive medical and educational facilities designed to supply a complete range of services for some 200,000 retarded. These centers provide diagnosis and continued counseling at no cost, and guide parents to the best available training programs. They also help to find foster homes for children whose parents cannot care for them.

Baltimore's John F. Kennedy Institute for Habilitation of the Mentally and Physically Handicapped Child, one of 27 university-affiliated research facilities created under a 1966 federal law, brings together pediatricians, psychiatrists, speech and hearing specialists. The institute puts children through complete physical and psychological examinations and tests for learning and perceptual disabilities before staff members meet with parents to set what Dr. Robert Haslam, the institute's director, calls "realistic goals for their habilitation." It also provides in- and outpatient services for 140 children. Similar programs are carried out at the Developmental Evaluation Clinic at Children's Hospital Medical Center in Boston, whose director, Dr. Allen Crocker, believes that almost every retarded child can be helped in some way. He spends much of his time training parents to accept the retarded as human beings. Parents must also learn not to give up hope. Joseph and Jean Paulsen of Chicago were told that their son Donny would never sit up or walk, let alone go to school. They were urged to put him in an institution. Instead the Paulsens kept him home and worked with him themselves so that Donny, 15, now not only walks, but dresses and feeds himself. Even mongoloids, once written off as hopeless cases, can be trained or educated to some degree.

Doctors at the Fairview State Hospital in Costa Mesa, Calif., have adapted a musical teaching method to help develop language skills. In one exercise, the youngsters sit in a circle and chant,

"Names, names, what's your name?" As they do, they pass a drum from hand to hand and each tries to say his name while beating out its syllables. Promising results are also being obtained with a behaviorist approach that does not concern itself with the cause of a child's disability or with traditional IQ measurements. It merely rewards positive responses from the child to any kind of lesson. The system seems to work with tokens that the children recognize as symbols of success. The point is to get the child accustomed to learning what he can, whether it is tying shoelaces or writing his name.

There are hopeful trends in other areas as well. Some states have enacted laws explicitly recognizing the rights of the retarded to proper care and treatment. New York provides tuition grants of \$2,100 a year so that children who cannot be placed in public schools can be served at places like the Kennedy Child Study Center, a school run by the Archdiocese of New York, and other private facilities. A federal court in Pennsylvania has ruled that the state cannot refuse to educate a child because he is mentally handicapped, and that decision is expected to encourage favorable decisions in suits now in preparation across the country. Federal Judge Frank Johnson Jr. in Alabama, citing the 14th Amendment, has struck a blow against the inhuman conditions in large institutions. His unusual decision last month laid down specific guidelines for upgrading services for both the mentally ill and the retarded.

Despite the quickening progress in the medical, educational and legal aspects of retardation, it would be illusory to think that any major victory over this age-old affliction has been won. The sophisticated diagnostic and training techniques that seem so promising are available to only a small minority of those who need them. The National Association for Retarded Children estimates that at least half the nation's mentally backward youngsters receive no schooling at all. Among adult victims, a large majority have the capacity for useful work; employers generally find them to be steady and reliable. But the necessary vocational training and special arrangements are often unavailable.

**Human Ecology.** In its 1971 report, the President's Committee on Mental Retardation appealed for an era of "human ecology" in which the incidence of retardation could be halved by the year 2000. That goal is not impossible, but its achievement will prove arduous. Science has already taken great strides toward the prevention of genetic and chromosomal defects and is likely to make more progress in the next 28 years. Elimination, or at least control, of many of the diseases that cause mental retardation is also within the reach of modern medicine.

But elimination of environmental

**retardation requires more than science; what is needed is a variety of strong antidotes for the poisons of poverty.** Prenatal care, for instance, would have to be universal and sophisticated enough to assure such things as proper nutrition for the expectant mother and the new infant. Better delivery of general health care for the very young would make it easier to spot defects. Just as public and private groups dispense helpful information about cancer and heart disease, similar groups could do a great deal to educate parents about their children's intellectual needs, about the danger signs to watch for, about sources of expert help. Preschool programs such as Head Start would have to be expanded to reach more children at the earliest possible age. Day-care centers are also useful, both for detecting problem cases and stimulating young minds.

The resources—public and private, in terms of money and know-how—necessary for these and other programs are enormous. Thus the prospect is not for rapid breakthroughs in mental retardation, but for chipping away at a problem that will persist in major proportions indefinitely. Meanwhile, some parents will feel that they are on the same journey that Pearl Buck described in her book about her own retarded daughter, *The Child Who Never Grew*, that they are taking their children "over the surface of the whole earth, seeking the one who can heal."

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