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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

