How the Kennedy family's own misfortune spurred the fight against a widely misunderstood affliction.

Hope For Retarded Children

By EUNICE KENNEDY SHIRVER

Forty-three years ago this month in Brookline, Massachusetts, my mother and father were looking forward with great anticipation and joy to the birth of their third child. My oldest brother, Joe, was four years old, bright, strong, aggressive, with dark eyes, a fine smile. Jack, quick, slender, independent—even at three he was interested in everything and adored by everyone. My father was thirty and my mother was twenty-eight. They loved children and would be happy to have all that God would send them.

Rosemary was born September thirteenth at home—a normal delivery. She was a beautiful child, resembling my mother in physical appearance. But early in life Rosemary was different. She was slower to crawl, slower to walk and speak than her two bright brothers. My mother was told she would catch up later, but she never did.

Rosemary was mentally retarded.

For a long time my family believed that all of us working together could provide my sister with a happy life in our midst. My parents, strong believers in family loyalty, rejected suggestions that Rosemary be sent away to an institution. "What can they do for her that her family can't do better?" my father would say. "We will keep her at home." And we did.

For years these efforts seemed to work.

My parents and the other eight children tried to include Rose in everything we did. At Hyannis Port I would take her as crew in our boat races, and I remember that she usually could do what she was told. She was especially helpful with the jib, and she loved to be in the winning boat. Winning at anything always brought a marvelous smile to her face.

She loved music, and my mother used to play the piano and sing to her. At the dining table Rose was unable to cut her meat, so it was served to her already cut.

Later on, in her teens, it was more difficult for her. In social competition she couldn't keep up. She learned to dance well enough for my brothers to take her along to parties, but it wasn't easy when Rose would say, "Why don't other boys ask me to dance?"

Yes, keeping a retarded child at home is difficult. Mother always said the greatest problem was to get other children to play with Rose and to find time to give her all the attention she needed and deserved. Like many retarded persons, Rose loved small children and wanted to be helpful with them. Often I heard her offer her assistance to Mother with a question like, "Can I take the young children rowing, Mother?"

She loved compliments. Every time I would say, "Rose, you have the best teeth and smile in the family," she would smile for hours. She liked to dress up, wear pretty clothes, have her hair fixed and her fingernails polished. When she was asked out by a friend of the family, she would be thrilled.

When my father became ambassador to England, Rose came to London with us and was presented to the king and queen at Buckingham Palace with Mother, Dad and my sister Kathleen.

Mother was worried about Rosemary in London. Would she accidentally do something dangerous while Mother was occupied with some unavoidable official function? Would she get confused taking a bus and get lost among London's intricate streets? Would someone attack her? Could she protect herself if she were out of the eye of the governess? No one could watch out for Rose all the time, and she was now a grown-up girl.

In 1941, when we returned to the U.S.A., Rosemary was not making progress but seemed instead to be going backward. At twenty-two she was becoming increasingly irritable and difficult. She became more and talked less. Her memory and concentration and her judgment were declining. My mother took Rosemary to psychologists and to dozens of doctors. All of them said her condition would not get better and that she would be far happier.
"Rosemary was different. My mother was told she would catch up, but she never did."

Furthermore, science is making great strides toward unlocking the causes of retardation. There are more than 200 known syndromes or conditions which can result in some form of mental retardation. Today scientists know how to prevent retardation in many of these cases, and there is reason to believe we are on the threshold of more exciting new discoveries.

Establishing a Foundation

In 1946 my father established the Joseph P. Kennedy Jr. Foundation as a memorial to my oldest brother, who was killed in the war. Not a single private foundation was then devoting its money to mental retardation, so we dedicated our efforts, and roughly $1,000,000 a year in grants and awards, to this effort. In recent years my husband, Senator Kennedy, and I have become increasingly active in the foundation as other interests began to occupy my father's time. My brother Ted took over as foundation president. Our work has given us a close acquaintance with the problem and how it is being handled, and with some of the mentally retarded themselves. I also served recently as a consultant to the President's Panel on Mental Retardation, which was commissioned to recommend a national program to deal with the problem.

I remember well one state institution we visited several years ago. There was an overpowering smell of urine from clothes and from the floors. I remember the retarded patients with nothing to do, standing, staring, grotesque-like misshapen statues. I recall other institutions where several thousand adults and children were housed in bleak, overcrowded wards of 100 or more, living out their lives on a dead-end street, unloved, unwanted, some of them strapped in chairs like criminals. In the words of one expert, such unfortunate people are "sitting around in witnessless circles in medieval prisons." This is all the more shocking because it is so unnecessary. Yet institutions such as these still exist.

One sun-drenched morning this summer my husband and I visited a completely different sort of center—the Southbury Training School near Waterbury, Connecticut. As we arrived, a fishing contest was taking place around a pond. In another area a group of girls sat knitting. Nearby another group sat cross-legged, engaged in a spirited community sing. A wooden "Toumenville" train pried the grounds, filled with laughing children. A coachman in red silk livery conducted pairs of children around green meadows in a burro-drawn cart.

Every person in this scene, old and young, was mentally retarded. The tendency had grown to look for retarded people, not afraid and then only after the train had grown to look for retarded people, not afraid and then only after the train had been able to tell the truth, all of us were a little afraid."

Who or what was there to fear? Should anyone be afraid of Wendell, a nine-year-old boy with the mental ability of a boy of
four? He and Timothy, my own three-year-old son, did many things at our day camp at the same speed and proficieny and loved each other. Both picked up their clothes—with some prodding—after swimming; both caught and threw a ball with the same ability, although Wendell kicked much better than Timothy. Both had the same table manners. Sometimes they would throw the food and would then have to go without dessert. Both ran about the same speed and rushed back and forth. Wendell and Timmy would hold hands and run down the hill together. Wendell would help Timmy climb up the hill when he was tired. Older retarded children are frequently more helpful to younger children than older normal children.

Discovering Latent Talents

Two things at the camp especially impressed the counselors. First, the retarded children were manageable with the right approach. The counselors, like others who have worked with the retarded, learned that the child with the lower IQ is often friendlier than the brighter child, not as demanding or self-centered, and that he often responds to affection as a bee to honey. Second, the counselors discovered that the retarded child may be capable of demonstrating unsuspected skills; that Veronica, for instance, could paint an appealing likeness of the President and his family standing in front of the White House; that a boy who couldn’t read or write was the best natural athlete in the camp.

The same assets of stability and unsuspected talent have made possible important breakthroughs in the employment of mentally retarded persons. There is no excuse for these people having to live neglected lives in the dark garrets and medieval institutions which are hangovers from yesteryear.

At the Wyoming Valley Workshop in Wilkes-Barre, Pennsylvania, there is a slightly built girl of twenty who had never been out of her house or spoken to anyone except her parents until just two years ago. In her first month at the workshop she was “terrified if anyone so much as looked at her,” according to director Walter H. George. Now she is the fastest producer of silk bows—for ladies’ pumps—on the workshop assembly line.

A teen-ager at the same center, which is one of a number of sheltered workshops in the United States today, wasn’t quite satisfied with the accuracy of a complicated metal jig developed by a shoe company at a cost of $300. He took a block of wood, two finishing nails and a dozen eyelets purchased from the ten-cent store and designed his own version of the jig at a cost of twenty-four cents. The new jig is more accurate than its predecessor. It is used by the workshop in producing ornaments for Wilkes-Barre shoe manufacturers.

In Tampa, Florida, J. Clifford MacDonald, the parent of a retarded child, saw the need for job opportunities for the mentally handicapped there. Working
"Here for once, at Southbury, the mentally retarded were participating as human beings."

A few months ago Doctor Cooke was interviewing the mother of a severely deformed infant when he noticed a skin rash on her arm. Checking further he discovered she had been given heavy doses of a prenatal drug in connection with the rash during the vital formative days just after her baby was conceived. At this point, of course, she did not even know she was pregnant. A team of scientists on the Johns Hopkins staff is now studying how certain damaging drugs and viruses can be transmitted to an unborn child through the mother's body. These are believed to be important cause of retardation.

Parents of retarded children have their hands full at home. But these dedicated people have found time to join hands to make a concerted attack on the general problem. Beginning in 1950, they have organized more than a thousand chapters of the National Association for Retarded Children. They have insisted that formerly unconcerned scientists and public officials consider the needs in this field. In addition, the institution established the first diagnostic clinic for the retarded and the first sheltered workshop.

Sometimes the persistence of an individual parent is the instrument which breaks important new ground. A New England mother of two severely retarded children taught from doctor to doctor in the story that her children's diapers "smelled different". She was scoffed at. One doctor even suggested she consult a psychiatrist for her own sake.

But she was right. Her children's retardation was caused by phenylketonuria, or PKU, a disorder which brings an excess of a certain acid to the system. The acid gives a distinct odor to the urine. Not until the doctors finally took the trouble to investigate this mother's "probable" evidence was the nature of PKU discovered. Today it can be detected by simple tests, and cured before it damages a child.

Relief From Hydrocephalus

A Bridgeport, Pennsylvania, engineer named John Holter discovered doctors could not successfully relieve his baby of the dread hydrocephalus—water on the brain—because they lacked a workable drain to siphon off this fluid. The determined parent managed to devise such a tiny valve for use on his son. Today it relieves more than 16,000 children stricken by this important cause of retardation.

The public and the governments they support insist on knowing the needs of the retarded. Yet even today less is being done for them at the community level than for any other afflicted group. Those of us whose lives are touched by this tragic condition need help, but broad support is essential to meet retardation squarely and evenfently lick it. Interested citizens in any community could take on projects like these:

- Women's clubs or service-club auxiliaries could help expectant mothers make full use of the local prenatal clinics—or establish them if they do not now exist. Many expectant mothers get less attention from doctors than cows get from cattle breeders. Yet mental retardation often can be prevented if mothers get proper tests and guidance during their pregnancy and avoid damaging drugs and X-rays. (From all I have learned, it is not true that life does not begin at birth; it begins at conception. What a mother does for herself and her baby during pregnancy is just as important as anything she does in his life thereafter.)
- Sports and civic clubs—or even private citizens—can start recreation programs for the retarded. As we discovered at our summer camp, the children could do dentistry, ball, paint, ride and many other skills. It is startling that there are no special recreation programs for the retarded in 99 percent of American communities.
- Junior Chambers of Commerce or other business groups could start sheltered workshops for the retarded. Some 25,000 retarded people were helped by vocational training last year, but this does not even meet the needs of the State of Wisconsin. Write the National Association for Retarded Children, 360 Park Avenue South, New York 16, New York, for full information.

Championing the Cause

Twenty years ago, when my sister entered an institution, it was most unusual for anyone to discuss this problem in terms of hope. But the weariness of falsification of those days is no longer. The years of indifference and neglect are drawing to a close and the years of resistance, experiment, faithful study and understanding are upon us.

To transform promise to reality, the mentally retarded must have champions of their cause, the more so because they are unable to provide their own. Dr. Maria Egg, a German psychologist, has expressed this as movingly as anyone I know in this passage from Ein Kind Im Ausland ("A Child is Different")

The blind had their Helen Keller; they had many other famous people in their ranks; the deaf had Beethoven and other outstanding personalities. Among the feebleminded there is none who, through his achievements, can contribute to the public his value and the value of those afflicted like him. It is up to us, then, to uphold the value of these human beings. It is up to us to help extend respect for human dignity to these creatures also; it is up to us who live with them and love them. For we know what they need and we know what they are able to do.
At Connecticut's Southbury Training School, retarded youngsters romp in a pool they helped build preparing for useful lives outside.