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POST

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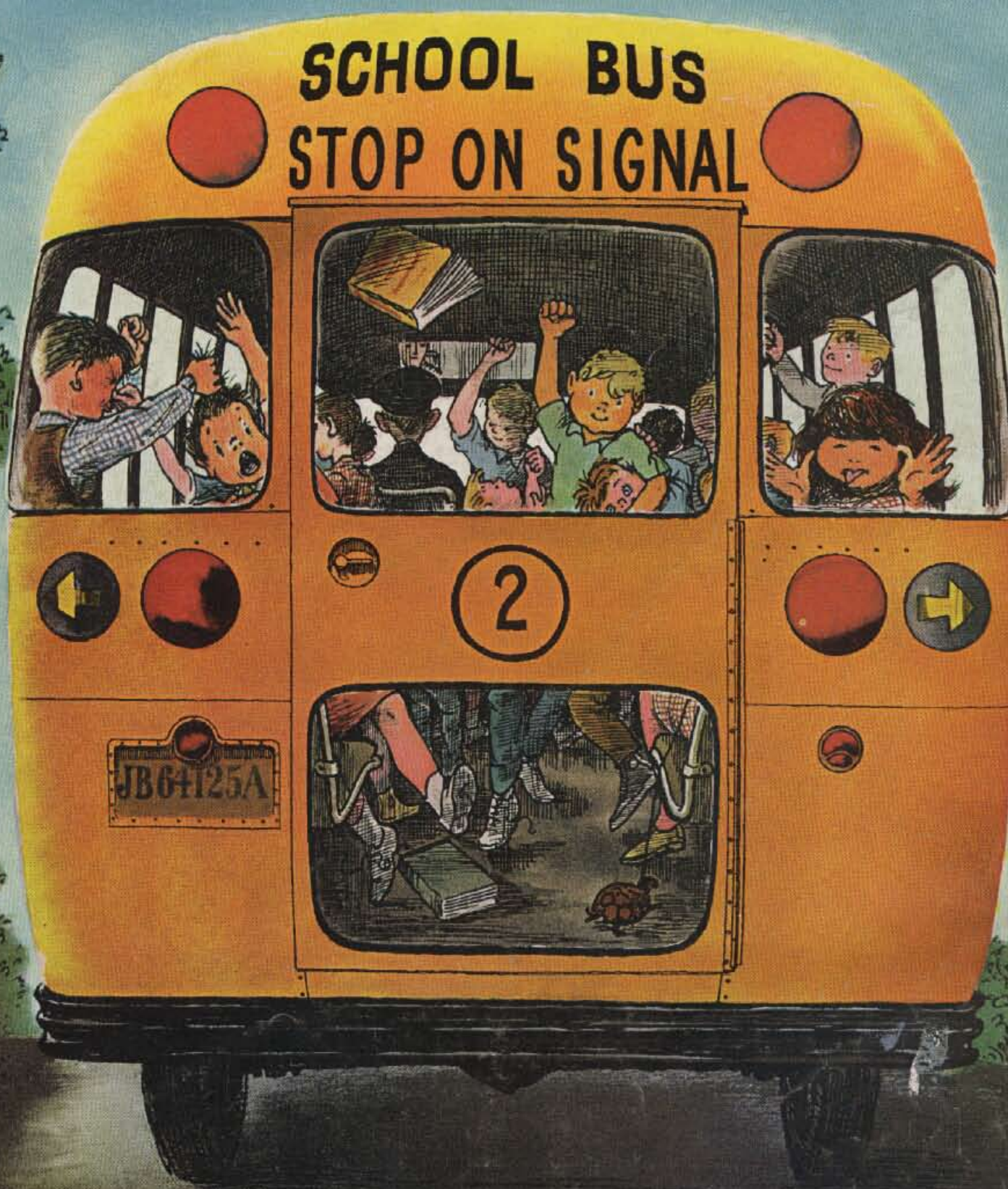
The Mood of America

A Cross-Country Survey By Stewart Alsop

Writing From Her Family's Own Experience:

Hope For Retarded Children

By Eunice Kennedy Shriver



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At Home With TV's Hazel

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At a day camp on her Maryland estate, Eunice Shriver enjoys a spirited ride with gleeful retarded children.

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

Hope For Retarded Children

By EUNICE KENNEDY SHRIVER

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 somber 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."



Rosemary (right) with Eunice and Jack two years before she was placed in an institution.

in an institution, where competition was far less and where our numerous activities would not endanger her health. It fills me with sadness to think this change might not have been necessary if we knew then what we know today.

My mother found an excellent Catholic institution that specialized in the care of retarded children and adults. Rosemary is there now, living with others of her capacity. She has found peace in a new home where there is no need for "keeping up," or for brooding over why she can't join in activities as others do. This, coupled with the understanding of the sisters in charge, makes life agreeable for her.

Like diabetes, deafness, polio or any other misfortune, mental retardation can happen in any family. It has happened in the families of the poor and the rich, of governors, senators, Nobel prizewinners, doctors, lawyers, writers, men of genius, presidents of corporations—the President of the United States.

A son of Stanley High, the late editor of the *Reader's Digest*, is in a training school for the retarded. Nobel prizewinning novelist Pearl Buck, in a small volume called *The Child Who Never Grew*, has written a moving account of her efforts to find a good life for her mentally retarded daughter. Roy Rogers's wife, Dale Evans, has written about their mentally retarded child.

There are, in fact, 126,000 babies born in this country every year who for one reason or another will not achieve an intelligence equal to that of a child of twelve. There are approximately 5,400,000 retarded children and adults in the United States—about 3 percent of our entire population. By 1970, because of the increase in population and the decrease in infant mortality, there will be over 1,000,000 more. Even now, mental retardation afflicts ten times as many people as diabetes, twenty times as many as tuberculosis and more than six hundred times as many as polio.

Chances for Useful Lives

And yet, as I have learned, we are just coming out of the dark ages in our handling of this serious national problem. Even within the last several years, there have been known instances where families have committed retarded infants to institutions before they were a month old—and ran obituaries in the local papers to spread the belief that they were dead. In this era of atom-splitting and wonder drugs and technological advance, it is still widely assumed—even among some medical people—that the future for the mentally retarded is hopeless.

The truth is that 75 to 85 percent of the retarded are capable of becoming useful citizens with the help of special education and rehabilitation. Another 10 to 20 percent can learn to make small contributions, not involving book learning, such as mowing a lawn or washing dishes. Only 5 percent—the most severely retarded cases—must remain completely dependent all their lives, requiring constant supervision.

Furthermore, science is making great strides toward unlocking the causes of retardation. There are more than 200 known diseases or conditions which can result in some degree of mental retardation. Today scientists know how to prevent retardation in many of these cases, and there is every reason to believe we are on the horizon 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 cause. In recent years my husband, Sargent Shriver, 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 witless 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 "Toonerville" train plied 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 teenager leading the group in songs was retarded. So were the children in the train, the passengers in the burro cart and their liveried coachman.

Here for once, at Southbury, the mentally retarded were participating as human beings, with all the privileges of work and play that the nonretarded enjoy. We saw a thirty-year-old man, with an IQ of 25,

hard at work cleaning up the yard. In many institutions he would have been sitting uselessly, permitted to do nothing, or even strapped in a chair. The children, we learned, had helped to build the train, and the school swimming pool. Adults go into neighboring communities on Saturday to cut lawns and do other household chores before returning to Southbury with some spending money.

Southbury is a community for the retarded, rather than an institution. Its 1540 acres contain many of the elements of everyday life—a farm, a bakery, a shoe-repair shop, beauty shops, barbershops, a clothing store and a cafeteria, most of them arranged on a typical small-town "Main Street." For the most part they are manned by the retarded. The emphasis is on rehabilitation rather than indefinite confinement. A team of first-rate psychologists and medical doctors does all it can to prepare residents for a return to the outside world.

There are 2000 "residents" of the picturesque cottages at Southbury, which is one of the five or six best state installations we have ever toured. Even though it has expanded greatly since it was founded in 1940, Southbury is far from able to meet the demand for admission. We learned that one parent—a U.S. Army colonel—arranged to be transferred from his California base to Connecticut when he learned about Southbury. Five years from the day he began his efforts, he succeeded in gaining admission for his son. Happily, there is a growing number of outstanding facilities, although the supply still falls far short of the need.

Prejudices of General Public

Unless a person has had intimate contact with the mentally retarded or has seen them under such conditions as those at Southbury, the mind's-eye impressions are likely to be deeply prejudiced. We discovered that anew this summer when we decided to use our Maryland farm, "Timberlawn," as a day camp for retarded children in the Washington, D.C., area.

Thirty-four children were referred to us by special schools and clinics in the area. At the same time, we recruited twenty-six high-school and college students—most of them with no prior experience along this line—to work as volunteer counselors during the three weeks of the camp.

What struck us immediately was that the counselors came to us with all the average prejudice and misunderstanding still current among the general public. They had heard, for example, that retarded children were "difficult," "unteachable," "helpless," "belligerent."

Ann Hammersbacher, an eighteen-year-old high-school graduate who came to work at the camp with her twin sister, Mary, told me afterward, "We had no idea what it would be like. We'd never met any retarded children. None of us really had any experience. 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 proficiency 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

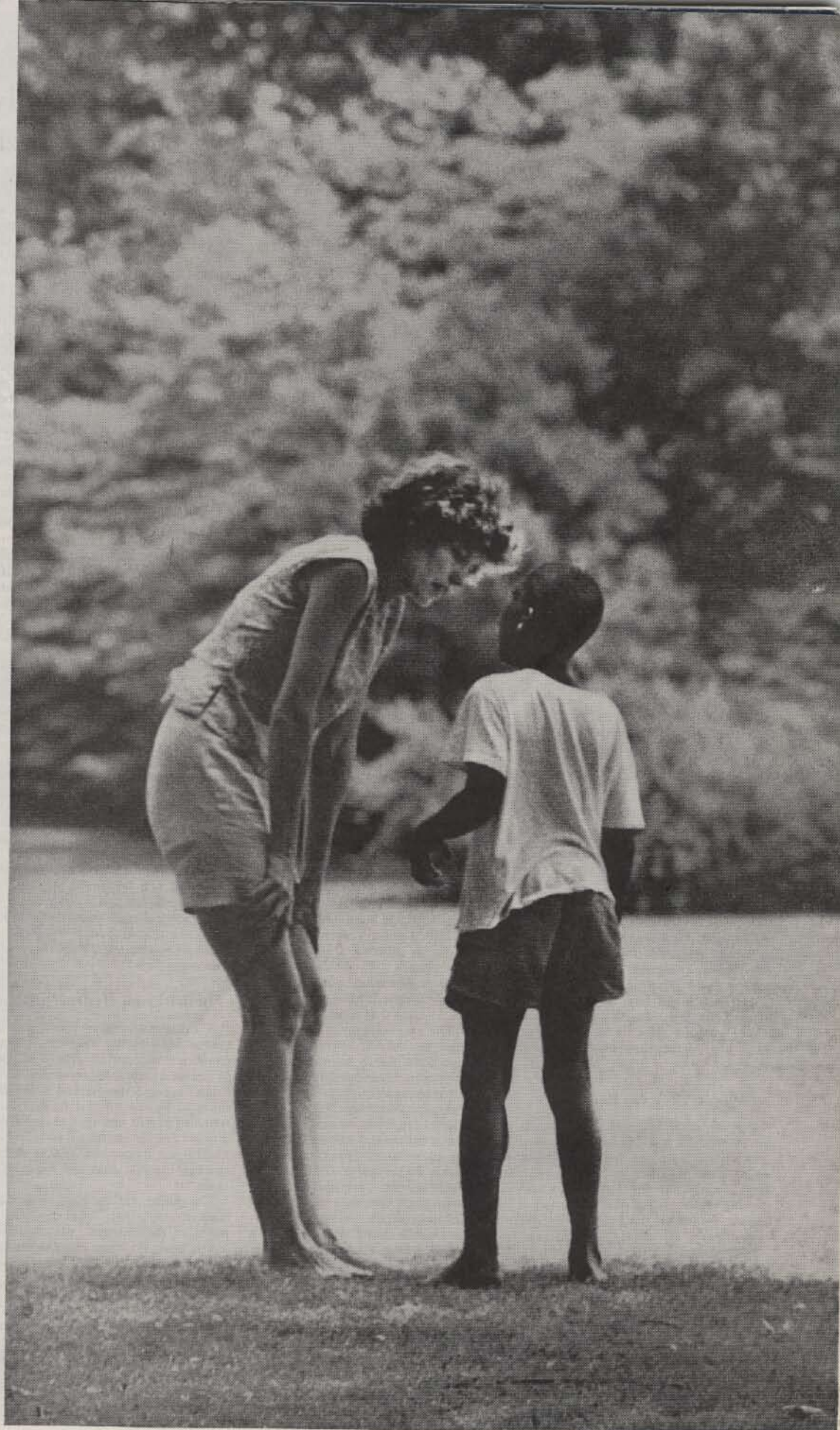
Two things at the camp especially impressed the counselors. First, the retarded children were manageable with the right approach. The counselors, like others who have worked with the retarded, learned that the child with the lower IQ is often friendlier than the brighter child, not as demanding or self-centered, 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



Eunice counsels Wendell, a nine-year-old with the mind of a child of four, during a lull at Shriver day camp.

"Here for once, at Southbury, the mentally retarded were participating as human beings."

with the United Fund, the MacDonald Workshop is among the best in the country, operating entirely on private contracts with area industry. Such centers achieve small miracles every day.

A number of large-scale business concerns are employing retarded people in less-skilled jobs. Bob Gordon, personnel director of the Remco Industries toy-manufacturing plant in Newark, New Jersey, which has employed the retarded successfully for ten years, points out that they often prove more stable than the average worker. "They're not so temperamental," he says. "They don't feel good one day and out of sorts the next."

Today, on New York's suburban Long Island, mentally retarded workers are using their skills in the highly competitive electronics industry. This started earlier this year after Mr. Hank Viscardi, head of Long Island's renowned Abilities, Incorporated, attended a meeting of the President's Panel on Mental Retardation. Mr. Viscardi, who was legless at birth, employs 400 physically handicapped workers.

"I wonder," he said to me, "if we could use similar training techniques with the retarded." Enthusiastically, I encouraged him to try; he picked the growing electronics field as a starter.

The International Business Machines Corporation and McDonnell Aircraft Corporation provided some contract work and training help, without which the program could not have been begun. Last spring about twenty retarded people started training at company headquarters on Long Island. Their average age is about eighteen, but their academic achievement in basic subjects is between the second and fourth grades. Few had much experience in the outside world.

At Abilities' electronics plant they learned such skills as cable lacing, wire preparation and soldering, and the assembly of transistor radios. Recently I was pleased to receive as a gift a radio put together in a few weeks by a retarded seventeen-year-old boy who had been functioning at the fourth-grade level in school when he came to Abilities. Now he is one of the stars of the training program.

"Won't They Go Berserk?"

Despite such successes, employment for the retarded is still in its infancy. One difficulty is ingrained public prejudice which is so damaging to these people. Mort Frankston, director of a work-training center for the retarded in Philadelphia, points up the problem. "I still have friends," he says, "who ask me, 'Aren't you afraid to work around retarded people? Won't they go berserk?'"

This is a misconception which we may as well clear up right now. There are important differences between the mentally retarded and the mentally ill. The vast majority of the mentally retarded are not emotionally disturbed. They do not "go berserk." They simply lag behind in their intellectual and physical skills, usually from birth. They often strike people as

odd in their behavior because the mind of a small child inhabits the body of a much older person.

To an average family, a mentally retarded child can mean not only a personal tragedy but economic disaster as well. I recall my father saying we have to think of the problem as it affects those with a total income of only a few thousand dollars rather than those with the "means" we were so lucky to have. The expenses could bankrupt many a family.

The Kennedy Foundation for years concentrated on building centers for the care of retarded children and, later, study centers for the diagnosis and treatment of this condition. But by 1956 it became apparent that no matter what we were doing for the retarded, the fundamental problems of the field were still there. Despite all private and public efforts, the children kept coming and coming, and there wasn't room for everyone. So we decided to concentrate on research to meet the problem at its source.

Attracting Researchers

To our surprise and consternation we found out that most doctors and scientists, like the general public, considered mental retardation a hopeless field for research. Established research scientists saw little connection between their studies and mental retardation. Young researchers wanted to do cancer or heart research and get dramatic results.

We decided to bring the mountain to Mohammed by endowing or building research laboratories in places where "our" problem could not be hidden from the Nobel prizewinners, the young researchers or any other men with ideas. Kennedy Laboratories were established at Massachusetts General Hospital, Johns Hopkins, Wisconsin and Stanford, where men such as Dr. Joshua Lederberg, Nobel prizewinner in genetics, are now active in the program.

Because of Rosemary, our family has been deeply involved. I have found it interesting to learn that some of the most outstanding accomplishments in this field have been made by persons who also have had a family member afflicted by retardation. The personal involvement often seems to bring an extra measure of dogged determination and faith.

The Johns Hopkins research effort, for example, is led by Dr. Robert Cooke, a brilliant silver-haired physician who is chairman of the Department of Pediatrics. He is the father of two retarded daughters who live at home with their three normal brothers and sisters.

Until recently most medical schools had no instruction in mental retardation. But Doctor Cooke has instituted at Johns Hopkins the first formal course on this subject at a U. S. medical school, with the help of five outstanding young scientists who have recently decided to concentrate in this field. This year 150 students, interns and residents took this advanced Johns Hopkins instruction before fanning out over the country to put it to use.

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 potent 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 system of its mother. These are believed to be important causes 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 they 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. The Norwegian mother of two severely retarded children trooped from doctor to doctor with 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 one doctor finally took the trouble to investigate this mother's improbable "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 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 has helped more than 16,000 children stricken by this important cause of retardation.

The public and the governments they support are slowly awakening to 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 families are touched by this tragic condition can help, but broad support is essential to meet retardation squarely and eventually lick it. Interested citizens in any community could take on projects such as 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 medical attention during pregnancy and avoid damaging drugs and X rays. (From all I have learned, it is clear 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 day camp, the children can swim, play ball, paint, ride and use 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 2500 retarded persons 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, 386 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 weary fatalism of those days is no longer justified. The years of indifference and neglect are drawing to a close and the years of research and experiment, faithful study and sustained advance 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 Ist Anders* ("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 feeble-minded, there is none who, through his achievements, could demonstrate 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 those creatures also; it is up to us who live with them and who love them. For we know what they need and we know what they can give us.

There is not one among the feeble-minded whose worth is revealed to mankind like a tall, burning flame, licking to high heaven, like those great personalities who overcome their handicaps. Despite all our efforts, the feeble-minded will always remain little flames. These little flames we must shield with our hands. . . . For these little flames radiate warmth and soothing quiet joy; they shine on the road that leads to the wisdom of the heart, to human maturity, and to true wealth.

THE END



At Connecticut's Southbury Training School, retarded youngsters romp in a pool they helped build preparing for useful lives outside.