
Useless People

The Kennedy family targeted mental retardation with good cause. In the 1950s, the mentally retarded were among the most scorned, isolated, and neglected groups in American society. Mental retardation was viewed as a hopeless, shameful disease, and those afflicted with it were shunted from sight as soon as possible. "There is no cure, no hope, no future," said one author, summing up social attitudes. "If you are once a mental retardate, you remain one always."¹

Mental retardation involves inadequate development of the brain in the womb or during childhood so that the person acquires subaverage intellectual functioning (below 70 IQ) and is unable to meet the stresses of daily life. MR affects about 2 percent of the U.S. population. Other developmental disabilities that strike in childhood, such as epilepsy or cerebral palsy (CP), also affect the brain—and may overlap with MR—yet they do not necessarily affect intelligence. There are many causes of MR. Some, such as Down Syndrome, are chromosomal in nature and involve the genetic material. Others are acquired in utero or in early childhood.² In up to half of all cases of MR, the actual cause is unknown. Yet, in the past, all converged to make the child an outcast, a social pariah, and that is the point of this chapter: that historically, people with MR were seen as useless, marginalized at the rim of society and deemed to be nothing more than burdens.

No agency of the federal government devoted itself to MR children, no foundation took up their cause, and the tiny voice of the nascent parents' movement barely made itself heard in the media and the corridors of power. Some

parents would send their MR children off to institutions and then publish notices of their death in the local papers.³ And when a child did die in these stinking MR asylums, he or she might be buried in an unmarked or numbered grave. This seemed fitting and proper for children thought to be lacking in their full humanity. Parents of retarded children could only welcome death for their afflicted offspring, said Pearl Buck, a Nobel prize winner and herself the mother of a retarded daughter.⁴ That was in 1950.

If You Had a Mentally Retarded Child

If you had a mentally retarded child in 1950, what would you do? What choices were there?

The initial news was often shattering. As parents with mentally retarded children looked back, their reaction to the discovery of the baby's condition stood out with crystal clarity. Crozet Duplantier, sports editor of the *New Orleans States-Item*, recalled hearing in 1956 the news from his wife when their baby boy, their first son after two daughters, was about a year old. "I'll never forget the words," he recalled. "Chris is retarded," his wife said. "He's a mongoloid [a Down Syndrome child]."

Duplantier's world "stood still for a moment." He remembered the same feeling in his stomach as when he was machine-gunned by the Japanese on the beach at Guadalcanal. But unlike combat, he said, "This problem would not go away. I was weak, sick, near despair as I realized that my first son was going to be a child all his life."⁵

Mrs. X, a housewife in New Haven, Connecticut, first learned the news from her own mother, who had cared for the baby while Mrs. X was still convalescing from the delivery. Three weeks after the baby's birth Mrs. X's mother told her, "He is not a well child."

"Not a mongolian idiot!"

"Yes," her mother said.

Mrs. X "went into hysterics." "I couldn't wait to get to the hospital. I couldn't wait! They didn't want me to go and tried to stop me. . . ." Now she knew why her husband "didn't get too enthusiastic about all my plans and hopes for the baby those three weeks. I couldn't understand his reaction."⁶

When Grover Powers, head of pediatrics at Yale, broke the news to another New Haven couple whose child had not sat up after twelve months, the mother "ran down the stairs crying with the baby" while the husband paid Dr. Powers. When she got back into the car with the friends who had driven them to the doctor's office, she was crying so hard she couldn't "tell them what was the matter."⁷

After parents recovered from the initial shock of an MR diagnosis for their child, shame was the next emotion they had to confront. In the high-functioning days of mid-century America, there was something fundamentally shameful about low intelligence. A diagnosis of MR for one's child suggested that perhaps you yourself—as the parent—were at fault because bad blood coursed through your veins. Pearl Buck's baby Carol was born in China in 1921. Pearl Buck recalled how accepting the Chinese were of any infirmity, and if they noticed anything at all would just laugh with the baby. But then one day on the streets of Shanghai, Buck learned that not everyone was so kind. "Two young American women walked along the street, newcomers from my own country, I suppose by their smart garments. They stared at my child and when we had passed one of them said to the other, 'The kid is nuts.'" From that day on, Buck began to shield her daughter.⁸

Upon returning to the States, Buck realized in common with other parents of MR children that the embarrassment was collective. "Parents have been bewildered and ashamed when their child is backward, when he cannot learn in school, when perhaps he cannot even learn to talk. . . . Neighbors whisper that So-and-so's child is 'not right.'" The parents pretend, perhaps, that the child is only slow. "The shame of the parents infects all the children and sorrow spreads its blight."⁹

If you elected to keep your child at home in 1950 rather than in an institution, you might conceal the child from neighbors. "Until the 1950s," said Wolf Wolfensberger, an MR specialist at the University of Syracuse who was to become a leader of the anti-institutional movement, "parents of handicapped children were isolated," hiding their children away "in attics and closets and sheds and basements."¹⁰ Neighbors might say, "I don't want my child playing with the retarded. It may rub off."¹¹

Thus, many parents were literally trapped along with their MR children. As Mr. G. of Brooklyn, the parent of a retarded daughter, wrote to a sympathetic congressman, "One cannot wholly comprehend the enormity of this problem, until they or their loved ones have been pierced by [this] arrow. . . . For some reason or other my child has refused to go out of doors. As a result she has been confined to her home for nearly eight long years.

"As a result my wife and I have gradually become a part of her own secluded little world. Now we are both beginning to feel that the walls are gradually closing in on us."

Mr. G. included in his letter to this congressman a poem he had written about his daughter:

Forgotten and bewildered she craves for affection,
 Always looking for kindness, love and protection.
 Her room full of toys yet this child is so sad
 Because her only companions are Mommy and Dad.

A doll in the corner and one on her chair
 Sitting so quietly the loneliness to share.
 The sun fills the room to brighten her day,
 But the neighborhood children with her do not play.¹²

Like the G.'s, other parents would find themselves withdrawing from life, from former friends and acquaintances. Said one New Haven mother in the mid-1950s, "I stayed a little more in the park by myself. . . . Rarely did we get a call from our friends any more." She avoided other people with children. "There would be hard feelings."¹³ One mother wrote to Eunice Kennedy Shriver, the member of the Kennedy family most dedicated to the cause of mental retardation, "Mrs. Shriver, my son is like the Christ Child. No one will take him in."¹⁴

So the task of raising the child would be solely on the parents' shoulders, and this vacuum of social isolation made it enormously difficult for parents to cope with their mentally retarded children. Aside from a community program in Minnesota going back to around 1920, there was virtually no local help to give a mother relief, no schooling for seriously retarded children. The philosophy of the day was, "Let the institution do it; it's their job."¹⁵

And so, in the pattern of the stay-at-home wife of the 1950s, mothers of MR children would stay at home, too. But unlike other mothers who had friends and community activities and for whom life seemed full, the mother of a special child had few options for socializing, for herself or her child. She would end up devoting her life to that child. Dale Evans, a country singer who was a movie star in her own right and wife of cowboy actor Roy Rogers, recalled the frantic struggle to get the baby to smile. This was in the early 1950s. The pediatrician kept asking her to make the child smile. "He said if a baby didn't smile until he was three months old, it meant that he was at least fifty per cent retarded in his mental growth." Dale "worked overtime" getting that baby to smile. She "had always been 'career minded.' Even when she was a young girl she wanted to succeed, and succeed *big*, in show business, and for a long time she put that career before everything else in her life." But after Baby Robin arrived, in August 1950, "it didn't seem to mean so much to her, after all."¹⁶

For those materially less well situated than the Rogers family, MR meant an endless round of visiting doctors and waiting in clinics, hoping finally

to get an exact diagnosis or some promise of therapy. The following example is one day in the quest of "Mrs. Brown," who lived in the Boston region, to establish what was the matter with her child: "We went to the clinic at 9 a.m. and it was 2 p.m. before we could get in to see the doctor. They wouldn't tell you when your name was coming up so you could go out for a sandwich. It was terribly disturbing because of all those screaming kids . . . all those deformed kids with their mothers changing and bottling them."

Then in walked one of "Dr. Black's" private patients. In two minutes she was seen.

"Oh boy," thought Mrs. Brown, "this is the way to go."¹⁷ But one had to be relatively well-to-do to become a private patient of the few doctors knowledgeable about MR.

Yet the parents who looked back wanted their bravery, rather than their despair, emphasized. It was a matter of pride to them that they kept their heads above water, and with apparent effortlessness to the outside world. But how exhausting it was to *seem* to be a well-adjusted MR parent. Janet Bennett, herself the mother of a Down Syndrome child, remembered watching another mother in a shoe store as that mother's "mongoloid daughter marched up and down among the racks, humming, clapping her hands, talking to her image in the mirror. Every bone, muscle, and nerve in the mother's body was concentrated on the task of appearing composed, at ease, unembarrassed." It was not enough to be just the child's mother, said Bennett. "What was more important was the role of 'well-adjusted parent,' of conveying the message to an ever-observing public that she was managing, she was doing well; it was not getting her down." The mother presented to Bennett's practiced glance "a picture of someone very hard at work in service to a relentless awareness."¹⁸ This relentless awareness was part of the cost of not putting the child in an institution.

It never stopped. Whether proud or humble, rich or poor, women who chose to keep their MR children at home endured a life of little else save caring for those afflicted children—as a report in 1974 by Marian Wright Edelman of the Children's Defense Fund put it—"all day, every day, for years, without outside support for [the children's] learning or their family's relief."¹⁹

What about putting the child in an institution? Although many mildly retarded children did stay at home, a significant number of those with severe retardation who reached adulthood did at some point in their lives find their way into an MR institution.²⁰ The institution towered over the MR scene in the first half of the twentieth century—a physician's first recourse, a last possibility for desperate parents.

Doctor's Orders

There were a few good institutions, such as the Vineland Training School in Vineland, New Jersey, where the numbers were small and the staff provided dedicated and caring service. Yet the vast majority of institutions for the mentally retarded were hell-holes. How could parents have consigned their children to such places?

The extraordinary policy of putting children in retardation warehouses far from home sprang mainly from the doctors. Thousands of parents were willing to contemplate saying goodbye forever to their small children—for that is what institutionalization truly entailed—only because their doctors were urging them to do so. Virtually all physicians immediately and insistently advised the parents to put the child away.

The experts of the day hammered this theme into medical audiences. At a 1947 meeting of the American Association on Mental Deficiency (AAMD)—the chief professional organization dealing with MR at the time—C. Anderson Aldrich, a pediatrician at the Mayo Clinic, called for “separation of Mongolian idiots from their mothers immediately after birth.” He advised physicians to explain to the mother “that the child is not strong enough to be brought to her for a few days.” Meanwhile, the father and relatives would be told that “no one is to blame” and the baby would be whisked away.²¹

Family doctors followed such advice unswervingly. When the doctor spotted “Mongoloid symptoms” in the three-week-old baby of Dale Evans and Roy Rogers, he told them to “put the baby in a ‘home.’” It was what he always advised in situations like this: “They’d have to give the child up sometime, anyway, and it was easier to do it quickly, before the child became entrenched in their hearts.” After the doctor left, Dale Evans was “so stunned she couldn’t answer.” Roy said no.²²

In 1947, kindly old “Dr. Albert” of Bloomington, Indiana, told John and Lorraine Frank, whose baby was born with MR, “Once it is clear that a child is hopelessly subnormal, there isn’t any question about the wisdom of institutionalizing the child.” Even though Lorraine might not intend to, the Franks would harm the child by keeping him at home, said Dr. Frank, and they would harm themselves as well. After this conversation, John Frank decided to place his young lad in an institution: it would be best for all.²³

One imagines the parents’ helplessness in the face of their child’s condition, and in their dependency upon the physician for advice. For many families, the crisis would come after the child’s first seizure (or “fit” as such episodes were once called)—a bewildering and terrifying event. (MR children often suffer damage to their central nervous systems, which