“Joey, when we began our work with him,” wrote psychiatrist Bruno Bettelheim in 1959, “was a mechanical boy.” Thus began a *Scientific American* article that is widely regarded as one of the first accounts of autism in popular American media. Bettelheim’s provocative narrative described a delicate 9-year-old boy with an empty gaze who, Bettelheim claimed, had “converted himself into a ‘machine’ because he did not dare to be human.” Although able to speak in a mechanical tone, he seemed lost in a world of ritual. Joey began every meal by stringing an invisible wire from an imaginary wall outlet to the table, “insulating” himself with paper napkins, and then “plugging himself in” before taking his first bite. He regularly connected himself to a “car machine” made of cardboard, tape, and wires and drew pictures of himself as a robot (Fig 1).1

Joey’s story illuminates how autism was understood in the 1950s, a time when the term was still new to many Americans. The Johns Hopkins child psychiatrist Leo Kanner had first described the syndrome in a 1943 case report recounting 11 children cut off from the world by what he called “extreme autistic aloneness.”2 Many had a prodigious talent for rote memory. Others, similar to Joey, were obsessed by rituals, spinning toys, and mechanical objects. Kanner had the field largely to himself until the 1950s, when Freudian psychoanalysts discovered and reinterpreted his work.3 They argued that autism represented nothing less than the emotional withdrawal of an infant at the hands of a cold and emotionally distant parent—the so-called refrigerator mother.4

No one did more to promote this theory than did Dr Bruno Bettelheim. A survivor of the concentration camp of Dachau, Bettelheim had emigrated to the United States to become a prominent public intellectual through a series of books that capitalized on postwar America’s infatuation with Freudian theory.5 As director of the Orthogenic School in Chicago, Illinois, a residential treatment center for young people with severe emotional disturbances, Bettelheim became fascinated by autistic children, whose avoidance of social contact reminded him of the withdrawal he had seen among concentration camp prisoners.6 In 1956, he obtained a grant from the Ford Foundation to observe a series of autistic children admitted to the Orthogenic School over the course of several years. Joey would become one of his most famous patients.

Bettelheim twice related Joey’s history, once for *Scientific American* in 1959 and in more detail several years later in his best-known book on autism, *The Empty Fortress.*7 According to both accounts, Joey was a colicky infant who spent much of his early life screaming for hours at a time. He had yet to speak by 18 months of age and was described as “remote and inaccessible” by his grandparents. Machines engaged him far more than did people, and at a surprisingly early age he learned to take apart and reassemble an electric fan. At the age of 4, when a special school finally raised the possibility of autism, he was spending much of his time rocking back and forth and his first mechanical obsessions had appeared. He refused drinks, for example, unless connected to an elaborate “piping system” constructed with straws.

Bettelheim had little doubt that Joey’s behavior represented his response to parental rejection. He related how his mother had first denied her pregnancy and after his birth wanted neither to see nor nurse him. She kept him on a rigid 4-hour feeding schedule (typical at the time for formula-fed infants), oblivious to her infant’s crying. Joey’s father was
less patient and sometimes “discharged his frustrations by punishing Joey when the child cried at night.” From Bettelheim’s perspective, Joey had no choice but to withdraw into his own world.1

Countless parents of autistic children in the 1950s and 1960s sought professional help only to be sent into psychoanalysis intended to help them understand how they had, perhaps unknowingly, rejected their child. Does Joey’s case history help us to explain how such a “bad idea” became so pervasive among the child psychiatry community? First, it is worth emphasizing that we have only Bettelheim’s side of the story, distilled from repeated psychoanalytic sessions. We have no independent corroboration. Second, Bettelheim and his contemporaries thought of autism as the earliest manifestation of schizophrenia, a diagnosis applied in the 1950s to a wide range of severe behavior disturbances in young people.8,9 Some of these children (especially those who presented after the first 3 years of life) may have developed delusional or withdrawn behavior after physical or sexual trauma. Child abuse, it should be remembered, remained largely unrecognized by the medical profession before the 1960s.10 Either way, extensive literature on what psychiatrists called the “schizophrenogenic mother” likely predisposed them to view parents’ motives with suspicion.11

For many in the autism community, the popularity of the refrigerator-mother hypothesis before the 1970s continues to be remembered as an example of what might be called “the tyranny of expertise”—the danger of giving professionals too much power. It is a theme that runs deeply in popular renditions of the history of psychiatry, portrayed in movies ranging from The Snake Pit to One Flew Over the Cuckoo’s Nest. Although significant questions have been raised regarding Bettelheim’s own credentials as a psychoanalyst, he did function as a public intellectual representing his profession in popular media.12 His story provides a bitter reminder that experts do not always listen and cannot always be trusted.

The most obvious legacy of the refrigerator-mother saga has, thus, been a willingness to question medical authority. This questioning reflects, of course, a broad social trend not limited to autism: patients since the 1970s have increasingly sought greater participation in decision-making in almost every domain of medical practice, both conventional and otherwise.13,14 Every physician who works with autistic children has encountered the formidable array of restriction diets, vitamins, and other alternative “biomedical treatments” embraced by many parents for autism despite a lack of evidence from controlled trials. The coalescence of the antivaccine movement around autism has become especially polarizing, pitting parents against one of the most valued tools in the pediatric armamentarium to promote child health.15,16

Yet, focusing on the theme of antagonism obscures the positive contributions made by many parents to research and treatment approaches in autism. It was, in large measure, thanks to parents that the refrigerator-mother paradigm finally collapsed. In 1967, for example, Clara Park challenged the psychogenic theory in The Siege, a firsthand account of her own autistic child.17 Bernard Rimland, a psychologist and parent of an autistic child, joined other parents to found the National Society for Autistic Children (now the Autism Society of America) to promote intensive behavioral interventions that have evolved to become the gold-standard treatment for autism.18,19 Eric Schopler, founder of the influential TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children) approach that uses parents as co-therapists for their own children, made

FIGURE 1
A self-portrait by “Joey” as a robot, symbolizing, according to Dr Bruno Bettelheim, the autistic child’s rejection of human feelings.
clear that he learned much of his approach from parents. Parents of autistic children have lobbied Congress for research funding and formed major foundations of their own (such as Autism Speaks, founded by an executive and grandparent of an autistic child) to promote research.

At a moment in time when the polarization over vaccines has created a deep rift between many parents and professionals, it is worth viewing today's conflict from the vantage point of history. Forgotten for the most part by physicians, the memory of the refrigerator-mother explanation of autism has fundamentally shaped the autism community. It is a story that continues to stand as a warning to the danger of shutting out the voices of parents in the name of a persuasive theory.

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