

# Development of autism research



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## Fighting the Monster

By writing a book called *Infantile Autism*, a Navy psychologist named Bernard Rimland established autism as an inborn condition rather than bad parenting. The book's popularity inspired him to launch the National Society for Autistic Children (NSAC). By forming an alliance and reaching out to parents, he gave the parents in his network a sense of hope and progress at a time when there was virtually no research in the field, setting the stage for the surge of interest in autism research.

Bernard Rimland was born in Cleveland in 1928, the son of Russian Jewish parents who emigrated after World War I. When he was twelve, his family relocated to San Diego, California. He got a bachelor's degree in experimental psychology from San Diego State University in 1950 and earned his master's degree a year later. He met Gloria Alf, a Jewish girl from the neighborhood, and got married before heading east to Penn State to earn his doctorate. After completing his degree at Penn State, Rimland was hired as the director of research at the new naval base in San Diego.

Their son, Mark, was born in the spring of 1956. But something was drastically wrong with Mark and it was only much later that his condition was determined to be early infantile autism. Besides reading everything he could on the subject, Rimland wrote a letter to Kanner in 1959 describing his son's behavior and announcing his intention to write a paper on the subject. After five years of research, Rimland published his book *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* in 1964, featuring an introduction by Kanner.

The crux of the book was that autism is primarily a product of genetic inheritance rather than family dynamics. At one point, he even referred to Asperger syndrome without explaining it. He suggested that in some cases the syndrome was caused by unknown environmental factors acting upon a genetic predisposition. He speculated that parents who tend to be gifted in certain fields pass this vulnerability down to their children along with the genetic factors for high intelligence. This hypothesis would fall into disrepute in the 1970s as studies by Michael Rutter and others proved that autism does not discriminate by IQ or educational level and is equally prevalent across all socioeconomic strata.

Rimland wanted the diagnosis to be strictly defined so that autism would turn out to be a metabolic dysfunction akin to phenylketonuria (PKU) that could be averted with a dietary intervention. PKU is a rare genetic disorder due to a gene mutation that impairs the metabolism of the amino acid phenylalanine. Untreated PKU can lead to behavioral problems, seizures, intellectual disability, and mental disorder.

To facilitate autism research, Rimland included in the book a questionnaire called the “ Diagnostic Check List for Behavior-Disturbed Children (Form E-1),” designed as a template for clinicians to copy and give to parents. After the book came out, Rimland unexpectedly received piles of completed E-1 forms. He followed up with the parents by telephone after scoring the checklist with a proprietary algorithm. He was so gregarious and empathetic to the parents that he became “ Uncle Bernie” to a generation of families.

In the second edition of his book, he included a revised version of the checklist called the E-2 designed for the parents to send to Rimland directly. His questionnaires had planted the seeds of a revolution.

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In the 1960s, most psychologists in America were still convinced that autistic kids were constitutionally incapable of learning. But a professor in the Psychology department of the UCLA named Ole Ivar Lovaas thought otherwise.

Ole Ivar Lovaas was born in Norway in 1927. He and his family were forced to work as migrant laborers when the Nazis occupied Norway in June 1940. After the war ended, Lovaas was allowed to immigrate to the United States on the strength of his violin playing. He got a music scholarship at Luther College in Iowa and earned his bachelor's degree in a year. Then he talked his way into the graduate program in psychology at the University of Washington in Seattle. He didn't want to become a psychoanalyst because he had lost patience with the speculations of theory-based psychiatry, so he focused on lab research.

After earning his doctorate at the University of Washington, Lovaas stayed in Seattle, teaching and conducting research at the Child Development Institute near the university. At the institute, he experienced that improving the language skills of children with developmental delays might help them control their problematic behavior. He was also influenced by a psychologist at Indiana University named Charles Ferster who proposed that parents had

inadvertently conditioned their children to be more and more autistic by rewarding their misbehavior with doting attention.

In 1961, he accepted a position as an assistant professor in the psychology department at UCLA. In his first year on the job, the Clinic referred only one child to his lab: a nine-year-old girl named Beth who spoke mostly in echolalia and bore scars all over from banging herself against walls and furniture. Lovaas outfitted a suite of rooms with one-way mirrors, hidden microphones, and a push-button device that enabled his assistants to record the frequency and duration of her behaviors. He called this style of intensive intervention applied behavioral analysis, or ABA.

Rimland was skeptical of the Lovaas method when he first heard about it. But he set his doubts aside and began to use the technique in training his eight-year-old autistic son. Lovaas had been thinking about inviting parents into the process because the lessons learned in ABA often didn't generalize beyond the artificial situation in the lab. The best hope for stimulating lasting behavior change was to train the children in their natural environment at home. Rimland arranged a dinner with Lovaas and a few of the couples from his network of autistic parents. Before the meal was over, they were begging Lovaas to train them in his method. By forming an alliance and reaching out directly to parents, Rimland and Lovaas had just built a shadow infrastructure for autism research in which parents, rather than medical professionals, were the ultimate authorities on their children's well-being.

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In the fall of 1965, Rimland received a letter from Ruth Christ Sullivan, a young nurse and mother of an autistic son. Sullivan proposed forming a national group to advocate for the needs of autistic children. On November 14, 1965, Sullivan, Rimland and 60 other parents formed the National Society of Autistic Children. In the coming years, parents would launch hundreds of local NSAC chapters all over the country. By the mid-1970s, the NSAC launched a number of legislations aimed at protecting the rights of individuals with autism and mandating services for them, especially education. Autism was also included in the Developmental Disabilities Act of 1976.

In 1974, by conducting thorough examinations of 78 children brought to the Children's Brain Research Clinic in Washington by NSAC members, the clinic's researchers theorized that autism is not a single clinical entity but is composed of multiple distinct subtypes. Rimland also did a groundbreaking study on savant skills based on data from his questionnaires, rediscovering the same clusters of enhanced ability in music, memory, art, science, mathematics, and technology that Asperger called "autistic intelligence."

Over time, the two paths represented by NSAC's founders – Sullivan's focus on services and Rimland's search for a cure – would diverge, resulting in Rimland being voted off the board of his own organization.

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Meanwhile, Lovaas was experimenting with alternating rounds of acquisition (reinforce proper behavior) and extinction (extinguish self-injurious behavior) trials on Berh. He found that she was responsive on acquisition trials, but not

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on extinction trials. So Lovaas sought a more expeditious solution, which was the use of punishment. Concerned that some of his techniques might seem unorthodox, Lovaas invited members of the press down to the lab to watch him in action. When the articles came out, members of the NSAC were concerned about how brutally kids were being treated at UCLA. Despite Rimland's tireless cheerleading for aversives, many NSAC parents refused to use them.

Meanwhile, state hospitals across the country embraced the harsh techniques promoted by Lovaas at UCLA as a way of keeping problem patients in line. In 1988, the NSAC (now changed the name to the Autism Society of America) has passed a resolution calling for a ban on aversive techniques. But painful electric shocks are still employed to punish autistic children at an institution called the Judge Rotenberg Educational Center in Massachusetts, even in the face of a public outcry against their use.

In the 1970s, Lovaas lent his expertise to a series of experiments called the Feminine Boy Project. The project's most celebrated success story was Kirk Andrew Murphy. Kirks was enrolled into the program at UCLA when he was five because his parents were concerned that he was exhibiting behavior that was too feminine. Lovaas worked with a graduate student named George Rekers who was Kirk's behavioral therapist. Rekers and Lovaas devised a program of total immersion based on Lovaas's work on autism. After sixty sessions in the lab, Rekers and Lovaas declared victory over Kirk's "sissy-boy" behavior. Rekers went on to build a career based on the premise that homosexuality can be prevented. He became a founding member of the Family Research Council, a faith-based organization that lobbies against gay-

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rights issues. In the meantime, Kirk committed suicide in 2003 at age thirty-eight, following decades of depression. His parents claimed that Kirk's earlier therapy had contributed to his suicide. In 2010, Rekers' days as an anti-gay champion came to an end when two journalists ambushed him at the Miami airport returning from a holiday in Madrid with a hired male escort.

In 1987, Lovaas claimed that nearly half of the children in an experimental group at UCLA had achieved “ normal intellectual functioning” by undertaking intensive ABA starting at age three. Lovaas's study was the breakthrough that many parents had been waiting for: empirical proof that their children could become “ normal” given enough devotion, effort, and expense.

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In 1964, Rimland received an invitation from the Center for Advanced Study in the Behavioral Sciences at Stanford University for a year's fellowship in Palo Alto. There he fell under the spell of Linus Pauling, who had won two Nobel Prizes, a Nobel prize in Chemistry, and a Nobel Peace Prize. Pauling was the most prominent advocate of the notion that megadoses of Vitamin C could avert the common cold, slow the aging process, and improve mood. Pauling's concept of orthomolecular psychiatry meshed perfectly with Rimland's thoughts on PKU and autism. Meanwhile, Rimland had started getting letters from parents claiming that their sons and daughters had become more calm and engaged after taking megadoses of certain nutrients, particularly vitamins B and C. After talking with doctors convinced of the therapeutic value of the megavitamin regimen, Rimland established



the *Institute for Child Behavior Research*, later renamed the *Autism Research Institute* in San Diego to launch a study. But he did not use the so-called double-blind placebo-controlled trial model in his study. Instead, he developed a home-brewed form of data analysis that he called “computer clustering”, an algorithmic search for clinically significant ripples in a sea of big data. With 45 percent of parents reporting that the vitamins “definitely helped” their children, Rimland was thrilled with the results of his experiment.

But three independent analyses of his dataset revealed more problems with his design. The design of the experiment with parents as evaluators of changes in their children’s behavior was anything but “blind” in the statistical sense. A Navy statistician with access to the raw data concluded that no reliable information about the reaction in the vitamins by various subtypes in the sample population could be obtained by using Rimland’s computer clustering scheme.

Rimland was bugged by the disappointing response of his peers to his megavitamin experiment. Noting the serious side effects caused by prescription drugs, Rimland concluded that the future of his work was not to be found in conventional medicine. He would eventually encourage his parent-experimenters to try several treatments at once, making it nearly impossible to tease out the benefits and side effects of any single one. This try-everything-at-once approach gave the parents in his network a tremendous sense of hope and momentum at a time when the mainstream science of autism was at a standstill.

From his office in Kensington, a suburb of San Diego, Rimland forged a productive alliance with the nineteen-year-old Steve Edelson, a psychology/sociology major in Lovaas's lab. Together they wrote a book called *Recovering Autistic Children* that became one of the bibles of the biomedical movement. In the 1990s, they launched *Defeat Autism Now!* (DAN!), the network of clinicians and alt-med practitioners that Shannon Rosa turned to for advice on the GFGC diet and other treatments after Leo was diagnosed in 2002.