Remodeling the Autistic Child

By BRUCE BOWER

Parents join clinicians to transform the tragedy of autism

The father of a 5-year-old autistic boy walks into Mifflin Elementary School in Pittsburgh, where the youngster is enrolled in a preschool program with both autistic and healthy children. The man throws his arms around program director Phillip S. Strain. The smile on his face speaks volumes. "Thank you for giving me back my son," he tells Strain.

Later that day, Strain meets with the parents of another autistic child in the program, known as LEAP (Learning Experiences . . . An Alternative Program for Preschoolers and Parents). Instead of smiles, their faces convey despair. "What have we done wrong with our boy?" the mother asks. "What have you done wrong?"

Contrasting reactions exemplify the sometimes triumphant, sometimes disillusioning outcomes of programs such as Strain's, which specialize in "behavioral treatment" – perhaps better known as behavior modification – for autistics. Teachers use praise, rewards and other nonpunitive tactics to promote appropriate behaviors in the classroom, and parents use behavioral techniques at home with children as young as 3 years old.

Encouraging signs indicate that round-the-clock behavioral treatment relying on parents as "home therapists" substantially improves the social and academic performance of some autistic youngsters, according to researchers at the annual meeting of the American Psychological Association (APA), held in New Orleans this past August. However, not all parents can or will carry the heavy burden of being an amateur behavioral therapist. And the long-term effectiveness of behavioral therapy for autism remains much in question, at times sparking intense debate even among those investigators using it.

Controversy is no stranger to the field of autism research. Since first described in 1943, childhood autism has witnessed a number of treatments heralded as godsends by some and denounced as failures by others. The push for new remedies no doubt reflects the mystery that surrounds the causes of autism and the dismal outlook for those afflicted with it: Fewer than one in 20 autistics become independently functioning adults living outside institutions or custodial care.

In rare cases, an autistic adult—such as Dustin Hoffman's character in the movie "Rain Man" – performs extraordinary intellectual or artistic feats.

Autism afflicts an estimated five of 10,000 persons, most of them male. The severity of the disorder becomes apparent early in life. Autistic children shrink from normal social relationships and never really connect emotionally and intellectually with the outside world. These youngsters avoid even the hugs of their parents. They often develop no language skills or mechanically repeat the words and phrases of others, a behavior called echolalia. Additional symptoms include repetitive behaviors such as rocking back and forth, prolonged tantrums, and in some cases head-banging or other forms of self-injury.

Psychoanalysts have suggested that emotionally disturbed, aloof parents produce autistic children. Psychoanalytically oriented treatment, which has fallen out of favor in the past 20 years, often removes autistics from their homes and attempts to create a healthy environment with clinicians taking on the role of supportive parents.

The prevailing view, however, regards autism as a biological disorder of unknown cause (SN: 9/6/86, p.154). Most behavioral researchers accept the biological hypothesis, but they attempt to treat autism by manipulating the child's environment with the parents' help.

The best-known behavioral treatment program for autistics began in the early 1960s at the University of California, Los Angeles, under the direction of O. Ivar Lovaas. In 1970, Lovaas and his co-workers admitted 38 autistics, all around 3 years of age, to a long-term study. They randomly assigned each child to one of two groups: 19 received intensive behavioral treatment, and 19 received minimal treatment. In addition, they tracked another 21 autistic youngsters who were not part of the program and who received no behavioral treatment.

For two or more years, intensive-treatment autistics underwent 40 hours a week of one-to-one treatment at home, administered by students trained in Lovaas' program. The children also entered public preschools. Parents received instruction in behavioral techniques to extend the treatment to all a child's waking hours.

Most behavioral treatment programs today employ the same training elements used by the staff, parents and, when possible, preschool teachers in the Los Angeles study. These include clear instructions to the child, prompting to perform specific behaviors, immediate praise and rewards for performing those behaviors, a gradual increase in the complexity of reinforced behaviors, and definite distinctions of when and when not to perform the learned behaviors.

Over three years, Lovaas, his co-workers and the parent-therapists aimed to reduce the children's aggressive behavior (in extreme cases, they used a loud "no" or a slap on the thigh), teach them to imitate adults' actions, establish appropriate play with toys and with other children, develop speech and language skills, teach basic reading, writing and arithmetic, and promote the verbal expression of feelings.

Children in the minimal-treatment group received fewer than 10 hours a week of one-to-one training from the staff. They were often enrolled in special education classes rather than public preschools. Their parents received no training as home therapists.

If any child in the project proved capable of starting first grade around age 6, contact with the Lovaas program was largely stopped, although occasional family consultations continued.

By age 7, minimal-treatment children in the study fared poorly. Their IQ scores, averaging around 55 at the study's outset, remained largely unchanged, and only one achieved normal social and academic functioning in a public school. The rest were in classes for autistic and retarded children.

In marked contrast, nine intensive-treatment children passed first grade in public school. Their IQ scores ranged from 94 to 120, in the normal to above-average range. Only two children in the intensive-treatment group had an IQ of 30 or less and were placed in classes for the autistic and retarded; the remainder had "mildly retarded" IQs and passed first grade in classes for the language-impaired.

The nine youngsters who succeeded in public school displayed average IQ gains of 40 points, Lovaas reported in the

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Phillip S. Strain

A teacher supervises classroom play at Mifflin Elementary School, where autistic and healthy youngsters jointly attend a special preschool program.

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In the most recent follow-up of the nine autistic success stories, described by Lovaas at the APA meeting, the children were interviewed and tested on both social and academic skills at about age 13 by psychologists unaware of their disorder. Eight of the nine autistic youngsters are "fully recovered," Lovaas says; psychologists could not distinguish them from a comparison group of nine healthy children.

But Lovaas' claim that intensive behavioral therapy for preschool-age autistics leads to normal functioning nearly half the time is not universally accepted.

"It's not possible to determine the effects of Lovaas' treatment," contends psychologist Eric Schopler of the University of North Carolina at Chapel Hill. For instance, he says, consistent attention from students untrained in behavioral techniques may also help young autistics, but there was no such control group in the Los Angeles study. Furthermore, Schopler notes, children given intensive therapy had above-average IQs for autistics – about 65 – and thus may have been more receptive to treatment than the majority of autistics would be. Parents of kids receiving intensive treatment are a select group in their dedication to the program, he adds. Many parents do not want to be co-therapists or may fail to use behavioral techniques properly because of divorce, personal problems, lack of interest or the mother's need to keep a job outside the home.

Successful autism treatment transcends specific techniques, Schopler maintains. He directs Division TEACCH, a statewide outpatient program in North Carolina for autistics and children with other developmental disorders. Parents can participate in treatment at one of five regional centers and in public school classes affiliated with the program. Activities and techniques based on a developmental assessment of each child become part of a "home teaching program." Behavior modification strategies are used but not emphasized.

More than 500 families with autistic children have entered Division TEACCH since its founding in 1966. About nine out of 10 children who complete the program with their parents are able to live at home or in community-based group homes, Schopler says.

Full recoveries such as those described by Lovaas are uncommon, he adds, and occur mainly among children who are echolalic rather than nonverbal and who have IQs above 50.

"Our success depends on a number of factors other than specific techniques, such as staff enthusiasm, community support and fostering a rewarding relationship between parents and their children," Schopler says.

Treatment at the LEAP preschool in Pittsburgh also goes beyond specific training techniques to include parent support groups and, when necessary, psychotherapy referrals for one or both parents. However, the year-round, three-hour-per-day preschool focuses on behavioral treatment in the classroom and on training parents as home behavioral therapists. In addition, the preschool enrolls normally developing youngsters from the surrounding community who help teachers demonstrate classroom tasks and behavior.

The first group of LEAP graduates – 10 healthy children and six autistics – is now about 7 years old. Normally developing youngsters, recruited from lower-middle-class families in a community with widespread unemployment, have profited greatly from the program, Strain says. Four of them now attend second-grade classes for the "gifted." Three of the six autistics have done well in public school; the rest are in classes for autistic and retarded children.

"We can't predict which children or families will benefit most from behavioral treatment," Strain remarks. Some autistics who enter the program with IQs below 50 and no sign of verbal ability do remarkably well, while others with higher IQs show little improvement.

Lovaas says individual responses to his intensive-treatment program are also somewhat unpredictable at the outset. "There's a slight tendency for children with higher IQs to end up in our recovered group," he acknowledges. But children who respond to behavioral reinforcement most quickly in the first three months of intensive treatment, regardless of IQ or echolalia, do the best socially and academically later on, he contends.

The ultimate effectiveness of behavioral treatment, including Lovaas' long-term project, remains unclear, says Strain, because of the small number of autistics studied so far.

Moreover, researchers remain uncertain which parents will most likely put behavioral training to good use. Parents are often reluctant to use behavioral techniques in public places, a necessary step in shaping independent behavior, Strain notes. If a child throws a tantrum in a shopping mall, a parent's instinct is to leave the mall and avoid a scene, not spend a few minutes redirecting the child's attention to a toy and praising him effusively when the emotional storm passes.

Another obstacle to behavioral treatment is a continuing feeling of pessimism expressed by some parents about the child's potential to improve, says Michael D. Powers of the University of Maryland at College Park. Powers and his co-workers operate a treatment program that integrates autistics with healthy youngsters in a Headstart preschool and trains parents in behavioral techniques for use outside of school.

After one year in the program, 11 of 12 autistic children showed promising advances in their play with other children and their ability to speak, Powers reported at the APA meeting. But several parents who use behaviorial techniques successfully still express doubt that their youngster will become self-sufficient, he adds. Some of these parents attribute a child's improvement to the "autism experts" rather than to the child. In one case, a father overlooked the effects of behavioral training and insisted his autistic youngster was just being stubborn.

Training parents as behavioral therapists is not enough, Powers asserts. For instance, families with autistic children need advice and assistance in developing a social life outside the home and in altering self-defeating attitudes about autism.

"Psychologists are moving beyond strict behavioral training with autistics and their parents," says J. Gregory Olley of the University of North Carolina, who works with Division TEACCH. "Some parents are lousy behaviorists. Nobody has asked parents what they need to handle their autistic kids more effectively. We've decided for them, and that has caused some of our problems." □