

Nudging Toward Normal

Step by step, skill by skill, applied behavior analysis taught Ben to talk.

BY JANE GROSS

PARAMUS, N.J.
It is lunchtime at the Alpine Learning Group here, and four preschool children assemble at a small round table and unwrap their sandwiches and juice boxes. The teacher prompts a sweet-faced 4-year-old named Ben to initiate a conversation with his classmate, Emily.

"Ask Emily 'Do you need a napkin?'" suggests the teacher, Deirdre Moon. Ben dutifully repeats the question.

"Say 'Here, Emily,'" Ms. Moon continues, showing Ben how to pass the napkin to the little girl. He imitates the gesture.

Now Ms. Moon turns to Emily. "Say 'Thank you, Ben.'" Emily thanks him.

Again, it is Ben's turn. "Say 'You're welcome,'" the teacher tells him. Ben is muttering to himself, staring into the middle distance. "Ben, look at me," Ms. Moon says. His eyes flicker toward her face. She repeats her instruction. This time Ben complies.

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Chris Maynard for The New York Times

As Ben plays, his mother, Yvonne, reinforces his learning with applause. Autism is no longer a lost cause.

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This lunchtime chitchat would be effortless for most children. But for Ben and Emily it is an achievement, since both are autistic.

Autism is the mysterious neurological disorder that strands children in a private world, oblivious to others, without the curiosity and instinct to imitate, which makes learning possible. Many have no meaningful language, are prone to tantrums that disrupt schooling and cling to ritualistic behavior like hand-flapping or twirling that take the place of play. Thus a simple social interaction between Ben and Emily deserves extravagant praise.

"Good job, you guys," Ms. Moon says buoyantly. "Awesome."

The number of children like Ben and Emily seems to be rising steeply, as documented in a new study in California that found an increase of 273 percent in the number of children with profound autism from 1987 to 1998, a number that continues to increase. Some experts attribute this in part to improved diagnosis. Once children like these were considered lost causes, destined for an institution. But along with a growing caseload is new confidence in one form of treatment, applied behavior analysis.

A.B.A. is the only intervention that has proved successful in controlled experiments, although small and unreplicated. The method has its roots in the research of B.F. Skinner, who developed a system of modifying behavior with rewards and punishments. His early techniques have been refined through the decades and found to be helpful with autistic children. Then came news that recovery was possible for some children: a 1987 study by O. Ivar Lovaas at the University of California at

Los Angeles followed 19 autistic children under age 4 through a regime of 40 hours a week of one-on-one behavioral therapy. Nine of 19 children, generally those with higher I.Q.'s, achieved normal cognitive functioning. Followed into adolescence, these children were found, as well, to be socially indistinguishable from peers, shy in some cases but not outside the normal range.

This early, intensive behavioral intervention is now recommended by an array of experts, including the National Academy of Sciences, which issued a report in 2001 urging at least 25 hours a week. But fewer than 10 percent of autistic children receive it, the academy says, because of long waiting lists at special schools, shortages of trained therapists and difficulty persuading districts to pay for this particular treatment when more generic special education, while less effective, would be much cheaper.

Many parents, Ben's among them, initially react with horror at seemingly robotic techniques. How can a 2- or 3-year-old — the typical age at diagnosis — sit still for hours and hours, bombarded with commands and rewarded for compliance with bits of food, special toys or squeals of praise?

Ben's mother recalls her initiation to the treatment. Ben was 2 at the time, newly diagnosed. He had no speech and spent most of his time at the window ledge pushing a toy train back and forth, stroking his own cheek and ignoring his parents and twin brother, Oliver. Heeding the advice of a network of parents with autistic children — and unwilling to experiment with unproven treatments like milk- and wheat-free diets, swimming with dolphins or mercury cleansing — the family reluctantly agreed to try an A.B.A. home program, supervised by Alpine's outreach staff.

The first goal was to get Ben to sit in a chair, make eye contact and follow simple instructions, all

prerequisites for language and learning. "Without basic attending behaviors, a child will just run around the room and flap," says Ben's father, Adam. (Adam and Yvonne, both tax lawyers, asked that their surname and hometown not be published.)

Reinforcing Ben's efforts with M&M's, a chance to turn the pages of "Cat in the Hat" and constant praise for "Good sitting!" and "Good looking!" the little boy gradually accepted the chair and the eye contact, the tools of engagement. But for the first two weeks, or so it seemed to Ben's distraught mother, Yvonne, the house in northern New Jersey rang with anguished howling.

"Many times I thought to myself, 'You're out of here,'" Yvonne recalls about the therapists. "It was heartbreaking to hear him so upset. He's a little boy. I wanted him playing in the park. Then I remembered he didn't know how to play in the park."

Ben's progress was swift. He mastered simple things like pointing when he wanted something or playing peekaboo. Slowly and methodically, the therapist's physical and verbal prompting was "faded," in the jargon of behavior analysis, and reinforcements for success made less tangible and immediate. The skills were generalized to natural situations, like a family celebration or a trip to the store. Tantrums were discouraged by ignoring them or redirecting Ben's attention elsewhere.

These outbursts usually have a reason, therapists say, like avoiding a task. Ben was taught to seek relief in a less stigmatizing way, like asking for a break. Anytime he was tantrum-free for five minutes, calculated on a kitchen timer, there were special rewards.

By summer, just before his third birthday, Ben was speaking, the most promising of signs. "Some children respond more readily and rapidly," says Bridget Taylor, co-founder of the Alpine Learning

Jane Gross covers education for *The Times*.



Ben is helped by Danielle Spinnato, left, and Corrie Davidson at the Friends Neighborhood School.

Chris Maynard for The New York Times

Group and a leading researcher in the field. "We just don't know in advance who those kids are." (I.Q. may be an indicator of success, although the test is less reliable in children without speech.)

The four variables, Dr. Taylor says, are the age when treatment begins, the quantity of therapy, the quality of therapy and the neurological potential of the child — whether, for instance, autism is coupled with mental retardation. "We have control over the first three," Dr. Taylor says. "No. 4 becomes apparent over time," generally between age 5 and 8.

Until last fall, Ben continued his therapy at

public special education classroom was sufficient, leading to costly litigation if a family had the conviction, stamina and money for the fight.

Like many such schools, the Alpine Learning Group was founded by parents; the first classes were held in 1988, with four children in a church basement. It now ranks among the most respected programs, along with the Princeton Child Development Institute and the Douglass Developmental Disabilities Center at Rutgers University. Its outreach program serves 14 children up to age 5. The school itself has 27 students, ages 3 to 21. Some of the younger children, 11,

Investigating Autism

ABOUT AUTISM

- Characterized by impaired social interactions, a delay in language development, and patterns of behavior like compulsive repetition or routines.
- Signs begin before age 3.
- Boys are four times more likely to be autistic.
- Studies show that intensive and early behavior therapy can bring significant improvement.

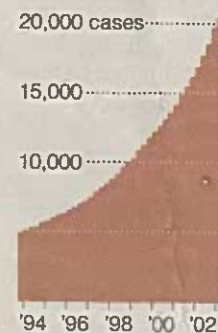
RELATED DISORDERS

- **PDD-NOS** (*Pervasive Developmental Delay-Not Otherwise Specified*) Often the diagnosis when a child has some but not all of the behaviors associated with autism.
- **Asperger's Syndrome** Characterized by normal or above-average language skills coupled with impaired social skills and nonverbal tasks.

THE NUMBERS

Reliable national figures are not available, but studies in California and other states show an increase in the number of cases.

AUTISM IN CALIFORNIA



POSSIBLE CONTRIBUTORS

- **Improved detection** As awareness has increased, fewer cases are overlooked or misdiagnosed.
- **Changing definitions** The classification of autism has been broadened, most recently in 1994.
- **Environmental triggers** Theories range from vaccines to exposure to toxins like heavy metals or viruses.

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Until last fall, Ben continued his therapy at home — up to 30 hours a week, one on one. His parents were similarly trained, so they could consistently reinforce what Ben was learning. “You have to keep on top of it every waking minute,” Yvonne says. “And when you’re tired, the temptation is to say, ‘Just this one time.’”

BEN’S family has been luckier than most in finding and paying for this kind of care, which became wildly popular after the 1993 publication of “Let Me Hear Your Voice,” an account by a mother of her two children’s recovery from autism, with Dr. Taylor, then a graduate student, as their teacher. With interest at a new high, skilled A.B.A. teachers, who charge \$40 to \$100 an hour, were scarce. The family’s goal was 30 hours of treatment a week but they could rarely find qualified therapists for that many hours.

At first, Ben’s family paid thousands of dollars out-of-pocket for his teachers. The state of New Jersey expects school districts to pay for a disabled child’s education after age 3 but itself supports only two hours of treatment a week before then. Months of exhausting back and forth with their insurance company eventually produced some reimbursement.

The next hurdle was finding a preschool spot and getting the state to agree to pay for it. Again, Adam and Yvonne were blessed.

Already familiar to Alpine directors from the outreach program, they were offered a coveted slot when another preschooler made the transition to a mainstream kindergarten. And their home school district approved the placement without protest, agreeing to pay the \$60,307 for a 12-month school year, including case management, home visits, the training of family and staff and gradual mainstreaming for children ready for it. Some districts might have insisted that a

ed programs, along with the Princeton Child Development Institute and the Douglass Developmental Disabilities Center at Rutgers University. Its outreach program serves 14 children up to age 5. The school itself has 27 students, ages 3 to 21. Some of the younger children, like Ben, are candidates for mainstreaming, although others never master the necessary language, social and behavioral skills to get by in a regular classroom. The older students at Alpine are more impaired, being readied for jobs and some degree of self-sufficiency in group homes. Obviously, that is not what their parents hoped at the beginning. But untreated they might have been institutionalized, which over a lifetime is far more expensive than even this costly form of education.

Last fall, Ben began at Alpine, working one on one from 9 a.m. to 2:45 p.m. with either Ms. Moon or another teacher, Danielle Spinnato. Formal lessons are interspersed with so-called incidental learning, like the scene at lunch. Four times a week, after school, Ben has two hours of therapy at home. Often Oliver is included and he helps guide Ben through make-believe birthday parties and board games.

Applied behavioral analysis is a way of life, lived 24/7. Immersion is essential because learning to clap, wave or point can require hundreds of repetitions for an autistic child. Hand-washing and similar self-help skills are taught one step at a time: Pull up sleeves, turn on water, wet hands, get soap, rub hands together, rinse off soap, get paper towel, dry hands, throw towel away. Tantrums and other idiosyncratic behavior must be all but eradicated if a child is to attend a regular school, go to church or take a family vacation.

This winter, Ben has worked on more than 40 academic, social and self-help programs, each with a defined objective, step-by-step teaching method and measurable goal. His programs, filed in a fat black binder, include “requests preferred items from a peer,” “puts on a shirt,” “follows instructions from a distance,” “answers questions

recently in 1994.

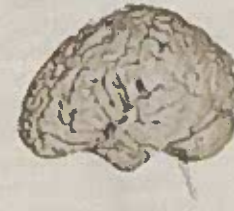
- **Environmental triggers**
Theories range from vaccines to exposure to toxins like heavy metals or viruses.

'94 '96 '98 '00 '02

RESEARCH



WITH AUTISM, AGE 3



NORMAL DEVELOPMENT

- Brain development appears to go awry in infancy. This “growth without guidance” leads to larger brains among autistic 3-year-olds.
- At least a half-dozen genes have been implicated in the disorder.
- Studies are under way to improve screening techniques and to examine the effects of the environment and the immune system.

WEB SITES

- Association for Science in Autism Treatment
www.asaonline.org
- Association for Behavior Analysis
www.abainternational.org
- National Alliance for Autism Research
www.NAAR.org
- Autism Society of America
www.autism-society.org
- Cure Autism Now www.canfoundation.org

Sources: Dr. Eric Courchesne and Dr. Karen Pierce, Children’s Hospital, University of California, San Diego (photographs courtesy of Dr. Courchesne and Dr. Pierce); Dr. Eric Fombonne, California Department of Developmental Services; Bridget Taylor, Alpine Learning Group

Kathleen O’Brien/The New York Times

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