

The Autism Fight

Susan Sheehan, The New Yorker- 12/1/2003

Regina Wagner began to realize that there was something wrong with her son Daniel when he was eight months old. He wasn't sitting or crawling, as her first child, Katie, had done at that age. Over the next year, Regina had more reasons for concern. Daniel didn't make eye contact with her or with her husband, Dan, and he didn't say Mama or Dada. Daniel's pediatrician attempted to reassure the Wagners. "Boys do things later than girls," he said. At eighteen months, Daniel said a couple of words, but he soon stopped. He did not respond to his name. He didn't like to be touched or held. He flapped his hands and feet. At the Sugar Plum Daycare Center, in Bethesda, Maryland, which he and Katie attended five days a week, Katie played joyfully with other children. Daniel remained in his own world and often bit other toddlers who came near him.

In October of 1997, three months before Daniel's second birthday, the Wagners took him to be evaluated at Georgetown University Medical Center's Child Development Center. During the evaluation, Daniel wandered around the testing room, pushing away test materials he was offered. He banged and threw blocks, instead of stacking them. Given a toy car to play with (pushing a toy car over a flat surface is considered an eight-month-level skill), he turned it upside down and spun its wheels. The testing revealed that Daniel's cognitive and behavioral difficulties were "consistent with a diagnosis of Autistic Disorder."

Parents of autistic children rarely forget the details of the day they are first given the child's diagnosis. Dan Wagner remembers asking one of the psychologists, "Are you telling me that Daniel won't be a quarterback at Harvard?" He also remembers her reply: "Well, actually, he may not graduate from high school."

Dan Wagner grew up in Montgomery County, Maryland. His father, a graduate of Harvard, was an electrical engineer; his mother was a teacher. (Both are retired.) "I'm the black sheep in my family," Dan says. "My older brother and sister are college graduates, but I dropped out of the University of Maryland to become a policeman in D.C." He married young, and has a son and daughter by his first wife. (Both children graduated from college; the son is a financial planner, the daughter a film director.) Dan, a tall, lean man of fifty-six with a full head of gray hair, is a homicide detective sergeant. He supervises a group of younger detectives, and his work hours are demanding and always changing.

Regina, a pleasant-looking woman of thirty-eight with brown hair and brown eyes, was raised on Manhattan's Upper West Side. While attending law school at Catholic University, in Washington, she worked as a part-time law clerk at the United States Attorney's office, and met Dan when they worked together on a case. "I never liked dating men my age," she says. After Regina and Dan were married, she took a job as an assistant state's attorney for Montgomery County, where they settled.

The Wagners' third child, Grace, was born a few weeks before Daniel's evaluation at

Georgetown; she was a much easier baby than Katie (who had been clingy) and Daniel (whom Regina described as "a lump" during his first few months). Grace looked directly at her parents and smiled. She crawled early and walked early. At twelve months, however, she still wasn't speaking. Three months later, she, too, was given a diagnosis of autism.

DIAGNOSIS

In 1943, Leo Kanner, a psychiatrist at Johns Hopkins University, wrote a paper in which he vividly described eleven children with severe social, communication, and behavioral problems, including extreme aloofness and indifference to other people. He applied the term "early infantile autism" to these children. The medical profession was slow to embrace Kanner's term. As late as 1968, the scientific literature was still using the label "childhood schizophrenia." Kanner originally believed that bad parenting played a role in the origin of autism. He later changed his mind, but other physicians subscribed to the bad mother theory long after Kanner discarded it. When autism was diagnosed in Daniel Wagner, Regina was devastated by the implication, which still lingered in the psychiatric literature, that she was somehow to blame for his condition. The person who was best known for putting the onus on "refrigerator mothers" was Bruno Bettelheim, the director of the Sonia Shankman Orthogenic School at the University of Chicago from 1944 to 1973. After his death, by suicide, in 1990, some of his former patients, now adults, asserted that they had been physically abused by Bettelheim while in his care.

In 1956, a psychologist in San Diego named Bernard Rimland and his wife, Gloria, had their first child. The Rimland baby screamed and resisted being held in the nursery of Mercy Hospital from the very day he was born, and kept screaming and resisting throughout his infancy. The prevailing psychogenic theory of autism made no sense to Rimland: he and his wife hadn't had a chance to do any parenting. In 1964, Rimland published a book called "Infantile Autism," in which he concluded that autism was not caused by bad parenting but was an organic disorder with a strong genetic component. The book played a significant role in changing the world's perception of autism. Today, autism is accepted as being a complex developmental disorder of the brain that interferes with the brain's normal development.

Autism is considered a "spectrum" disorder. Among the disorders on the spectrum are classic autism, the diagnosis that both Daniel and Grace Wanner received, in which children suffer from a triad of symptoms (impaired social interaction, a delay in or a total lack of spoken language, and difficulty with motor skills); Pervasive Developmental Disorder-Not Otherwise Specified (P.D.D.N.O.'S., also known as atypical autism), in which a child has some but not all of the deficits associated with autism; and Asperger's syndrome, which is characterized by average or better-than-average language skills but impaired social skills. Autism is four times more common in boys than in girls; Asperger's is ten times more common in boys.

Because of the medical community's long-standing fixation on bad parenting, biomedical research was neglected for decades. Only a few researchers were seriously focusing on autism in 1994, when the National Alliance for Autism Research was established and

became the first non-governmental organization committed to biomedical research on the disorder. Last week, federal officials convened a national conference in Washington to unveil an ambitious ten-year plan to address the problem. Among its many goals, the program will provide funding to help identify the disorder's genetic and environmental causes, provide better services for children suffering from it, and train therapists to better help them.

Recent studies suggest that autism spectrum disorders occur in an estimated one in every two hundred and fifty children. Ten years ago, the number was thought to be one in twenty-five hundred. Theories attempting to explain the increase range from citing improved diagnostic tools and public awareness--children once considered "eccentric" might now be labelled autistic--to blaming environmental factors. Much attention has been focused on the possible role of childhood vaccines as a precipitating factor; a recent Danish study found no evidence for that theory.

Autism is believed to involve between ten and fifteen genes. There is currently no in-utero test for autism, as there is for Down syndrome. There is no simple dietary intervention for autism. Every few years, new miracle treatments for autism have been touted and subsequently discredited. Some parents are proponents of "floortime" (getting down on the floor and playing with the child, letting the child take the lead in playing) and others of having the child swim with dolphins, but no studies on the efficacy of such treatments have been published. So far, only one study has provided any real hope for parents.

In the late nineteen-seventies, a Norwegian-born psychologist named O. Ivar Lovaas began a study at U.C.L.A. on sixty autistic children. Children in the study's experimental group received forty hours a week of an intensive, highly structured form of behavior modification called Applied Behavioral Analysis. The therapy was administered by student therapists trained at U.C.L.A. The parents were also trained in therapy, so that supplementary treatment could continue for most of the children's waking hours. Children in two control groups received only ten hours of therapy a week, with no supplemental parent training.

The study was published in 1987. The children in the three groups were compared at the ages of six and seven. Nine of the nineteen children (or forty-seven per cent) in the experimental group completed normal first-grade classes and were promoted to the second grade. In contrast, only one of the forty-one children (or two per cent) in the two control groups was placed in a normal first grade and promoted to a normal second grade.

The theory behind Applied Behavioral Analysis rests on the assumption that autistic children have inefficient neurocircuits--specifically, connections that are not as efficient as those found in normal children. In normal children, a connection may go from A to B, but in the autistic brain the connection may go from A to C to D to E before finally reaching B. Inefficient connections result in more "noise," which is believed to hinder social and cognitive development. Lovaas's therapy takes advantage of the brain's ability to adapt and be retrained. When people learn a particular skill, such as throwing a

baseball, they are reinforcing neurocircuits that are specific to that skill. When autistic children are taught a specific behavior through constant repetition, the therapy is training the neurocircuits to respond in a certain way and somehow teaching the brain to receive these signals, which would otherwise be drowned out in a sea of noise. In order to be effective, Lovaas has stressed, A.B.A. therapy must be started early, must be sufficiently intensive, and must be carried out in part by the parents.

TREATMENT

The children Daniel bit at the Sugar Plum Daycare Center had complained to their teachers and parents, and Regina Wagner knew that he would soon be asked to leave the school. She decided to quit her job to care for Katie, Daniel, and Grace at home, while also devoting her time to obtaining A.B.A. therapy for Daniel. It is probably fortunate that she had no idea of what lay ahead. Regina learned of a private non-profit organization, Community Services for Autistic Adults and Children (CSAAC), which provides A.B.A. therapy to young children with autism. Daniel was evaluated by CSAAC (pronounced "sea-sack") in December of 1997 and recommended for the program.

Regina then approached the Montgomery County Infants and Toddlers Program, which provides services and funding for autistic children under three years old. She was told that Daniel, instead of receiving funding for A.B.A. therapy, would be eligible for forty-five minutes of speech therapy, forty-five minutes of play therapy, and forty-five minutes of occupational therapy (skills like holding a cup and scribbling with a crayon), for a total of two and a quarter hours of therapy every week.

Believing that the success of A.B.A. is contingent on early intervention, the Wagners decided to hire a special-education lawyer to file an administrative complaint seeking to get Daniel into the A.B.A. program right away, and borrowed ten thousand dollars from Regina's parents for the attorney's retainer fee and for the initial work he did. The Wagners' suit began in February, 1998, and lasted until August, 1999. During that time, Daniel received only an hour or two of weekly speech-and-language therapy for six months; the costs were paid for by Dan Wagner's insurance. A speech-language pathologist said that Daniel had improved in his ability to "imitate" words and phrases, that is, to repeat words in a parrot-like manner without appearing to understand them. As for actual speech, at home Daniel usually said just one word--it sounded like "wah" to Regina--but he sometimes babbled.

Life in the Wagner household was dismal. Daniel often spent eight hours a day dangling a piece of string in front of his eyes. Sometimes he put the string in his mouth. He screamed if it wasn't precisely the way he wanted it, and he screamed when his parents took it away. The Wagners never gave Daniel string. He fabricated his own by tearing threads off a towel, a blanket, or a carpet fringe. He also tore up books, putting the torn pages in his mouth, making spitballs out of them, and sticking the spitballs on the television screen. "I hated it when Daniel destroyed books," Regina says. "I bought the same books again and again for Katie to read. They meant something to her."

When Regina tried to go out with Daniel, he flung himself on the pavement. He kicked and scratched her when she tried to pick him up. If the Wagners did get their children to a playground, Daniel screamed if he was put on a swing or a slide. He preferred to sift

endlessly through the pieces of cedar mulch below the equipment.

Sometimes Regina couldn't get Daniel into his car seat, because he arched his back and flailed; on more than one occasion, she had to cancel his doctor's appointments. Once, when Dan, Regina, Katie, and Daniel were waiting to check out at a Home Depot, the cashier ran out of change. Daniel started to scream and to punch himself in the face. Other customers glared at the parents. Regina felt terrible. The Wagners couldn't eat at McDonald's, and because Daniel was intolerant of waiting it was often hard for them even to order food at a drive-through window. "I became a prisoner in my house," Regina says. "Dan had to do most of the grocery shopping. He soon knew which supermarkets were open until midnight and which were open all night."

It was hardest for Regina when Dan, with his rotating job schedule, was working the midnight-to-8 A.M. shift. As Daniel got older, he became more violent toward Regina, and he started to bang his head against a wall. He rarely slept through the night. He often woke up between 2 A.M. and 6 A.M. and wanted to watch television. "He would grab my fingers and slam them against the TV," Regina recalls. "When I refused to turn it on, he bit me and pulled my hair and scratched me and kicked me. I had to call Dan at work. He told me to stay calm. He promised me he'd let me take a nap after he got home and before he went to bed for a few hours." Regina suffered from sleep deprivation and from her son's remoteness. "Daniel had no real idea who I was," she says. "He treated me like a piece of furniture. He imitated the words of the 'I Love You' song from 'Barney & Friends,' but he didn't know what the words meant. He never said, 'I love you, Mommy.'"

In May of 1998, three months after the Wagners brought suit to obtain Applied Behavioral Analysis therapy for Daniel, an administrative-law judge ruled against them. On January 19, 1999, while an appeal of that ruling was pending, Daniel turned three. The Wagners sought funding for A.B.A. therapy from Montgomery County Public Schools, which is responsible for educating children from ages three to twenty-one. The school district agreed to fund an A.B.A. therapy program for Daniel through CSAAC. By then, however, the CSAAC program was full, and Daniel was put on a waiting list. He could not start A.B.A. until August of 1999, the same month the Wagners learned that they had lost their appeal. The Wagners now owed the special-ed lawyer an additional twenty thousand dollars.

On Tuesday, August 31, 1999, Regina and Dan Wagner wheeled Daniel's stroller into CSAAC's offices in Rockville, Maryland, for an initial three-hour workshop. The CSAAC team included a psychologist, a special-ed teacher, and several therapists, including a twenty-year-old woman named Bonnie Dayhoff, who had been administering A.B.A. therapy since she was sixteen and a junior in high school.

A significant part of A.B.A. therapy is conducted with the therapist sitting in a child's chair facing the child. Daniel was told to "sit down." It took three therapists to get Daniel into a chair. Once seated, he was told to stand up, which required the therapists' help. The "sit down" command was given a second time. Daniel was again "prompted" into the chair--the therapists helped place him in it. Each small step in A.B.A. is repeated and

prompted until the child masters the step; then the physical prompts are gradually phased out.

Another step was to get Daniel, who tended to slouch in the chair, to "sit good." He was inclined to fidget, and was told to keep "hands quiet." He was praised for "good sitting" and for "quiet hands," and he was rewarded. The reward might be an M&M, a cracker, or the chance to play with a toy. Daniel had seen an Elmo Guitar on "Sesame Street" and there was one in CSAAC's clinic room. Someone gave it to him and he appeared interested in it. "One thing Daniel really had going for him was that he was easy to reinforce," Bonnie Dayhoff recalls. "He wanted certain objects. And, when we all clapped for him, he looked around the room. He clearly liked applause. Not all autistic children care."

After Daniel had a brief break, a therapist demanded his attention by saying, "Look at me." He was praised for "good looking." A three-piece puzzle was put on a table between the therapist's chair and Daniel's. The therapist handed him one piece of the puzzle, a pig, and said, "Put here." She took his hand and showed him where to put the piece. This was repeated a number of times. Each time Daniel put the piece in the wrong place, she again demonstrated where it went. When he put the piece in its correct place, she praised him and rewarded him with a treat. Daniel likes sweets and was willing to work for M&M's. After he put the first pig in correctly, he picked up the second piece, a pig of a different color and shape, and put it in correctly, and did the same with the third pig.

"I could tell from the first day that A.B.A. was going to work for Daniel," Regina says. "He responded to structure. He seemed eager to learn. He lit up like a light bulb when he did the puzzle. He had never done this before. I was so happy I was practically crying." Because Daniel had "receptive" language (he could understand words spoken to him) but negligible "expressive" language (he could speak only a few words, such as "All gone" and "No more"), CSAAC's goals for him in the 1999-2000 academic year included knowing and saying the letters of the alphabet, numbers, and the names of colors.

In September, CSAAC began to send therapists it had hired and trained to the Wagners' home. Four young women came for morning and afternoon sessions with Daniel for an average of thirty-six hours a week for a year. Dan Wagner built a therapy room for Daniel in the basement of the Bethesda town house where the Wagners were then living. At first, Daniel resisted entering the room and sometimes tried to escape, pulling the therapists' hair, hitting them, and scratching them, but he soon became more willing.

At the beginning of each session, Daniel was told to "sit down" and was reminded to sit properly. He was helped with the puzzle. He was praised. "So smart," "Very good," or "Wow," the therapists said, and they clapped, and they rewarded him with candy. Everything Daniel was taught was repeated a number of times in a session, and during subsequent sessions. Each therapist recorded Daniel's correct and incorrect responses to each skill that was attempted. Daniel's "behaviors" were also recorded. He was easily distracted and often threw himself on the floor, perhaps to try to avoid therapy: it was the first time in Daniel's life that demands had been made on him. The therapists are trained

to avoid making eye contact with children who are "tantrumming." It is hoped that, if the child learns that disruptive behavior brings no rewards, his tantrums will diminish and perhaps stop. If the child quiets down, he is praised for "good quiet." It is believed that autistic children rock, spin, or stare--or, in Daniel's case, fixate on a string, make spitballs, and twirl the tails of toy animals--in order to stimulate themselves, because they don't find appropriate behavior sufficiently engaging. Many autistic children continue to "stim" for months or years, but the behavior in some who do well in A.B.A. tends to decrease, as Daniel's did, at least while he was involved in therapy. Initially, his behavior improved outside therapy. "Daniel independently went into the therapy room to do a puzzle and called 'Mommy' so that I would come and look at it," Regina says. "I called Dan at work to say, 'He did it!' I could see glimmers of a child coming out of a dense fog."

Compliance is also a tenet of A.B.A., and Daniel slowly became more cooperative. After six months, he was less aggressive with the therapists, he responded to the "come here" instruction between sixty and ninety per cent of the time during a session, and he had fewer tantrums--an average of seven a week. As the therapy progressed, Daniel quickly learned to say simple words. When a therapist told Daniel what a ball was, or a boat, or a cat, he was able to say the words clearly and he didn't forget them. At the end of his first six months, he began to respond to the question "What is it?" not just by saying "Ball" but by saying, "It's a ball." He had more trouble pronouncing words with more difficult blends; for example, the "br" in "bread." His progress in receptive and expressive language skills was described in a February 23, 2000, report as "tremendous."

By then, Daniel was able to snap beads to one another, stack rings, and complete wooden puzzles of up to ten pieces. He knew all the letters of the alphabet. He was gradually acquiring abstract concepts. After the therapists taught him the words "triangle," "rectangle," "circle," and "square," and put two-dimensional and three-dimensional shapes on the therapy table, he was able to "put with same." Daniel learned hundreds of nouns and was proficient at putting them in correct categories--animals with animals, and vehicles with vehicles. "Not all autistic children learn so fast and not all are able to generalize," Regina says.

Therapy moved from Daniel's therapy room to other rooms in the Wagners' house. Daniel was able to use his words spontaneously to request some items he desired. He often said, "Want apple juice, Mommy," and, still more often, "Want computer." Daniel had first seen a computer in the office at the Sugar Plum Daycare Center and had been attracted to the mouse, which he didn't need to be taught how to use. He and Regina shared a computer--Daniel had seen her send countless e-mails to lawyers and subsequently to CSAAC personnel. He was able to do kindergarten-level computer programs when he was four.

Daniel's therapy also moved outside. When the therapists first started to take him on walks, he would try to run into the street, or "body drop," falling to the ground, or kick and scratch. Eventually, he learned that if he walked a few steps without throwing a tantrum he would receive M&M's. After a few weeks, he walked. That meant he could go

out of the house--and that Regina and Katie and Grace (in her stroller) could go out of the house--and to the playground. After several months, Daniel was able to go down a slide alone. And he was so occupied with the six hours of daily therapy that he often forgot about the string, and he was tired enough afterward to sleep through the night, and let his parents sleep.

At first, Katie Wagner was merely disappointed and embarrassed by having an autistic younger brother. Daniel couldn't be disciplined, for fear that he would bang his head or punch himself in the face, so Katie felt it was unfair for the Wagners to discipline her when she was naughty. Katie didn't want to go out in public with the family because of Daniel's strange behavior, and she couldn't invite friends to the house. The only easy hours of Katie's day were those she spent in school. After the family learned that Grace was autistic, Regina found Katie huddled in a corner one day. "Am I going to catch autism?" Katie asked. The Wagners took Katie to see Dr. C. T. Gordon, a pediatrician and child psychiatrist who specializes in evaluating and treating autism. Dr. Gordon assured Katie that autism was not contagious. Katie later wrote a letter to Dr. Gordon urging him to "hurry up and cure autism before the sun goes down." The Wagners were devastated by Grace's diagnosis and by their inability to start a treatment for her immediately. At the beginning of 1999, Grace was eighteen months old. Over the next year, she acquired no speech and went from being a sweet baby to being a wild toddler.

In April of 2000, the Wagners drove to a hotel in Parsippany, New Jersey, for a dinner to celebrate the seventieth birthday of one of Regina's aunts. The guests were seated at round tables for ten. Katie had a nice time with her cousins, and enjoyed the filet mignon dinner, but Regina and Dan had no opportunity to eat. Grace and Daniel wouldn't sit down. Grace ran from table to table, spilling the contents of the saltshakers into the guests' water goblets. The birthday cake was on a display stand. Before it was cut, Grace put her hand in it, scooped out a piece of cake, and ate it. Daniel ran into the kitchen, where there were many pots filled with boiling water, and was chased out. The Wagners had to keep removing both children from the dining room.

While Grace was still two, the Wagners learned that Montgomery County's Infants and Toddlers Program might be willing to pay for offering A.B.A. to some autistic children under the age of three, and they applied for Grace. CSAAC offered her what is known as a "workshop" model program. The Wagners would hire her therapists, and subsequently be reimbursed by Montgomery County. Grace began therapy on July 31, 2000, six weeks before her third birthday.

Grace resisted therapy more than Daniel did, but she did not have to be taught how to play with toys: she stacked rings; she stirred the pots on the toy stove in the therapy room that Dan had added to the basement for her, separate from Daniel's; she played with dolls. Language was far more difficult for Grace; at three, she had just started to talk. She "stimmed" less than Daniel, and showed more affection to people she knew and liked. But Grace was more ritualistic. She lined things up, and insisted that they be in a particular order--her order. She would line up the food on her plate. While being bathed, she would line up the washcloth, the shampoo, and the soap on the side of the tub.

"Everything had to be just so," Regina recalls.

One goal of A.B.A. therapy is to enable autistic children to attend a regular school and go to classes with "neurotypical" children. In September, 2000, Daniel began attending a private nursery school in Bethesda three afternoons a week, paid for by the Wagners. His classmates were three at the start of the school year. Daniel was four, and turned five in January. It was believed that younger children would be more likely to accept a child like Daniel, who was so obviously different. CSAAC provided a "shadow" for him--a therapy aide who drove him to school and helped him, as unobtrusively as possible, follow the teacher's instructions. She prompted him to behave appropriately. In addition to ten hours of shadowing, CSAAC continued to provide Daniel with about twenty hours a week of A.B.A. at home.

At five, Daniel was reading. "He could read 'War and Peace' and some of my law books, because he quickly grasped the rules of phonics," Regina says. "He didn't understand them. He could read and understand age-appropriate children's books." When Daniel was asked to read a story to the class, he did. He sometimes played with blocks and in the playground. Even so, he seldom interacted with his classmates. He often didn't eat the snacks that were served (although he recited the blessing perfectly at snack time); he wasn't inclined to color pictures during coloring time; he needed prompts to stay in line and to wait for his turn. CSAAC had started a toilet-training program for Daniel in August, but it was, by and large, unsuccessful. Daniel also threw frequent tantrums in school, as he continued to do at home and on outings to places like malls. "Transitions are tough for autistic children," Bonnie Dayhoff says. "When it came time for Daniel to leave places he particularly enjoyed, like toy stores, he carried on. Once, when I was on an escalator with Daniel at the mall, he body dropped. I put my back out to get him safely off the escalator."

With Grace occupied in her basement therapy room and Daniel and Katie at school, Regina finally had several hours at home to cook, clean, and do laundry. She had learned in the spring, to her surprise, that she was pregnant. In November, her doctor ordered her to bed; it appeared that the baby might be premature. The births of Katie, Daniel, and Grace had been happy. The mood in the labor room on December 1, 2000, the day George Wagner was born, was sombre. If a family has one autistic child, the chances of having another are between five and six per cent, and the Wagners already had two autistic children. After George's birth, Regina had a tubal ligation.

In the spring of 2001, Bonnie Dayhoff quit. She loved the work and accepted its hardships--she had scars on one arm from a boy who bit her a year after she began doing therapy--but the salary was low. She wasn't given time to eat lunch. Two clients lived forty-five minutes apart, and she had twenty minutes to get from one home to another. In a short period of time, she received three speeding tickets and was in three fender benders. She took a job with a psychiatric-rehabilitation agency. The therapy aides CSAAC subsequently hired for Daniel were less experienced. There were fewer of them, and, to Regina's dismay, Daniel's hours of A.B.A. were sharply curtailed. Many therapists are college students majoring in psychology who have an interest in

special education and are willing to work for low wages to gain experience. One of Grace's best therapists graduated in the spring of 2001 and moved to another city. Regina couldn't easily recruit replacements. When Grace's hours of A.B.A. were also cut back, her behavior became worse. In May, she threw a chair at a therapist, bit a therapist's ear, and threw a therapist's eyeglasses on the floor. She scratched Dan's face badly as he was putting her in her car seat. She scratched and kicked her mother often, especially when Regina was trying to dress her or was holding or nursing George. Grace avoided Daniel, because she had discovered that if she went after him he would retaliate, but she tried to bite, scratch, and kick Katie. She paid scant attention during her therapy sessions and was often "nonresponsive." She lost some of her previously mastered words and skills. She pronounced most of the words she had learned incorrectly, saying "boo" for "book" and "wan" for "want." (Most children do this initially; some autistic children persist in doing it.) She silently took people's hands when she wanted them to do something for her that she could do for herself

Like many parents of autistic children, the Wagners had no social life. They didn't give dinner parties or go to dinner parties. They didn't go to movies. Regina couldn't attend Katie's afterschool activities. The Wagners' town house in Bethesda was small, and the children were disturbing the neighbors. In the spring of 2001, the Wagners decided to move to a detached house, with a large yard, in Potomac, Maryland, eleven miles away. Regina found a school near Potomac, the Mill Creek Nursery School, which would accept Grace into a Monday-Wednesday-Friday afternoon class and Daniel into a Monday-to-Thursday afternoon class. Daniel was five, but Regina and CSAAC felt that he needed another year of preschool before attending regular kindergarten. The new home in Potomac had three bedrooms and two bathrooms on the second floor. The first floor had a separate dining room and living room, a powder room, and two small rooms off the kitchen, added by previous owners, which soon served as therapy rooms.

Like most autistic children, Daniel and Grace do not understand danger. Dan Wagner had to install locks high up on the outside doors so that the children couldn't reach them, even if they stood on chairs. Grace also suffers from pica, a tendency to eat substances like banana peels, sand, Play-Doh, and coffee grounds. If Regina makes coffee and doesn't empty out the grounds immediately, Grace eats some and makes mud pies with the rest on the kitchen floor. She climbs on the kitchen counter and helps herself to whatever she fancies: raw rice, salt, bouillon cubes. The Wagners' television set was housed in an entertainment center. It had shelves on the bottom. Grace used the lower shelves as if they were a ladder to get to the top. She fell off the entertainment center when she was three, breaking her clavicle. Dan replaced the shelves with cabinets that have lockable doors. In the living room of the Potomac house, a sectional sofa met in a corner. Grace's spot was on top of the sofa cushions, in the corner. She climbs because she apparently likes high perches.

Not long after Dan repainted the town house, Grace took a permanent black marker and scribbled on every wall of the living room-dining room; he had to repaint. In the Potomac house, Dan wallpapered the upper part of the living room and painted the lower walls. After Grace watched the video of "The Lion King," she scratched the walls. She had seen Mufasa clawing at the cliff after Scar pushed him off, and was apparently imitating him.

Explanations of Grace's behavior must always be speculative: she cannot answer questions beginning with "why." The Wagners have a lock on their refrigerator. There is a lock on their bedroom door, so that Daniel and Grace do not enter and toss all the clothes out of the dressers or go into their bathroom. Grace regularly makes the sink, toilet, and tub in the children's bathroom overflow; Dan's tasks include patching the kitchen ceiling, below, every few months.

LITIGATION

In the spring of 2001, Regina exchanged friendly emails with CSAAC's psychologist in charge of both Daniel's and Grace's programs. On April 6th, the psychologist emailed her, "Boy ... do we make a good team." But then, according to Regina, CSAAC began to lose therapy aides, and the number of therapy hours Daniel was receiving declined. In the following months, as a Maryland judge later put it, "a serious and irreconcilable rift" developed between the Wagners and the CSAAC administrators and staff.

Shortly before Daniel and Grace were to start attending the Mill Creek school, Regina learned that the therapist CSAAC would be providing as Daniel's "shadow" wouldn't be able to drive him to school on Tuesdays and Thursdays, because a morning client lived in another county. Grace's therapy aide couldn't drive Daniel, because the children were too likely to pull each other's hair in the back of her sedan, and Grace tended to bolt out of a car unexpectedly, requiring one's full attention. Dan Wagner rearranged his work schedule and drove Daniel to school two afternoons a week, waiting outside in the parking lot until Daniel's shadow reached the school.

It was especially important to Regina that Daniel attend Mill Creek; she hoped that he would be able to improve his behavior and social skills so that, with a shadow, he could enter kindergarten the following fall. He would need to sit still in a chair and on the floor, during circle time; to take turns; to answer questions; and to speak to his classmates. When the CSAAC psychologist informed her that in 2001-02 Daniel would not be entitled to transportation provided by the agency, Regina objected, and she complained about other aspects of the program--about the scheduling of clinic meetings for Daniel at CSAAC, and home consultations for Grace, for example. Now that Regina was no longer practicing law, she was entirely focused on obtaining treatment that would result in Daniel's being like the fortunate ones in the best-outcome group of Dr. Lovaas's original study--those nine children out of nineteen who had been able to attend school with other first graders and who had been promoted to second grade. When she believed her efforts were being thwarted, she sent numerous emails to CSAAC's personnel and frequently telephoned. Apparently, CSAAC's employees became worn out by Regina's persistence. And they may have been piqued by another act on Regina's part.

CSAAC is one of eleven sites in the United States and in other countries that are replicating the original Lovaas study. Other parents had complained about CSAAC's cutbacks in therapy, but only Regina decided to complain to Ivar Lovaas himself. In September, she emailed him about her problem with CSAAC. He emailed back that he had communicated with a CSAAC director. A week later, CSAAC made a complaint of its own--not to the Wagners but to the Montgomery County Public Schools district.

In a letter dated October 3, 2001, the CSAAC director and Daniel's psychologist expressed "serious concerns" to the school district about the appropriateness of the CSAAC program for Daniel. The letter alleged that over the previous two years the Wagners had failed to spend sufficient therapy hours with the children--only "6 hours (total) of therapy, out of the required 1,000 hours." It alleged that Regina herself had stated that she was unable to provide any therapy hours. It also alleged that the Wagners had failed to provide essential materials for Daniel's program, that the Wagners' transportation problems had hindered the scheduling of meetings, and that the Wagners had failed to participate in required training sessions. The letter recommended that Daniel's treatment be undertaken somewhere with "more comprehensive services, that will enable him to learn in a more structured environment." Neither CSAAC nor the school district informed the Wagners of the letter--a serious violation of procedure. The Wagners learned of it long afterward. On October 9th, the CSAAC psychologist sent Regina a letter saying she would no longer communicate with her by email.

By November, Regina was writing to the CSAAC director to express further concerns: Daniel's conversation program had not been updated in a year; his toilet training program had stagnated; all of Daniel's senior staff had recently left the program, and no one who had experience with Daniel could train newcomers. Daniel was repeating the same drills rather than moving on. Regina notified CSAAC that she and Dan planned to videotape Daniel's therapy sessions, so that CSAAC could see the evidence for itself. On November 14th, CSAAC informed the Wagners that it would not consent to videotaping, and told them that all services to Daniel would be discontinued pending a previously scheduled meeting between the Wagners and CSAAC on November 28th.

The purpose of the meeting, which was mandated by law, was to devise an Individualized Education Program, or I.E.P. for Daniel. The I.E.P. has been described as the "cornerstone" of the Individuals with Disabilities Education Act, initially passed by Congress in 1975. The impetus for the act was public concern about the widespread practice of school systems' relegating handicapped children to private institutions or warehousing them in special classes. To combat such exclusionary practices, the act mandates that all children with disabilities receive a "free appropriate public education" and that children with disabilities be "mainstreamed"--educated with non-disabled children--to the "maximum extent appropriate." For each child, an I.E.P. is to be developed that is, in the words of a 1982 Supreme Court decision, "reasonably calculated to enable the child to receive educational benefits."

At the November 28th meeting, the Wagners learned that the school district had recommended that Daniel attend a special classroom program for students with autism spectrum disorders at Maryvale Elementary School in Rockville, Maryland, effective immediately. Two days later, the Wagners visited Maryvale. There were eighteen autistic children in three classrooms. The program offered Daniel only twenty weekly hours of A.B.A.; there was much less one-on-one therapy; some of the kids were screaming. Daniel tends to imitate bad behavior, and the Wagners feared he might do so. In the Wagners' opinion, Daniel had made great gains since 1999 as a result of one-on-one

A.B.A. therapy. They believed that he had also benefited from having attended private nursery school with normal children. "Maryvale was in every way a change for the worse, one we felt sure would cause irreparable harm to a verbal autistic child like Daniel," Regina says.

Tension in the Wagner household had escalated during the weeks before CSAAC stopped providing services to Daniel. Regina and Dan Wagner began taking Prozac. On October 31, 2001, they had brought Grace and Daniel to see Dr. Gordon, the autism specialist; he had prescribed for both children the antipsychotic drug Risperdal, which is more customarily given to those suffering from schizophrenia. In small doses, it had a calming effect, which made the children more receptive to therapy. One of Risperdal's side effects is weight gain. Grace, a delicate child, remained slender. Daniel, more solidly built, soared from fifty pounds to ninety-nine pounds.

Daniel had stopped attending nursery school when CSAAC suspended his services, putting him in limbo. When Grace picked up her red book bag and left for school three times a week with her shadow, Daniel yelled, "I want school!" and banged his head on the floor and against the wall. He spent most of his time on the computer, rewinding videos, or twirling the tails of his stuffed animals. "It was the worst period of my life," Regina says. "It was worse than getting the original diagnosis. Daniel thought he was being punished and he had no idea why."

The Wagners informed the school district that they thought that Maryvale was inappropriate for Daniel. A few weeks earlier, before the I.E.P meeting, a placement specialist at the school district had recommended the Lovaas Institute for Early Intervention (known as LIFE), in Cherry Hill, New Jersey, which runs workshop programs based on Lovaas's A.B.A. research. LIFE serves some children in Maryland for whom CSAAC lacks sufficient personnel. The placement specialist had assured the Wagners that both children could easily be switched from CSAAC to LIFE. The Wagners now informed the school district that they would pursue the LIFE program for Daniel.

The district told the Wagners to enroll Daniel in Maryvale or file a due-process complaint with the courts. At one point, the district sent the Wagners a letter saying that if Daniel did not attend Maryvale or some suitable private institution or home-schooling program the district would notify "Protective Services." The Wagners applied for due process. They still owed twelve thousand dollars to the lawyer who had tried to get Daniel into an A.B.A. program before he turned three. They were fortunate to find a major Washington law firm to take their case on a pro-bono basis. Once they had filed for due process, a "stay put" order was supposed to go into effect. The reasoning behind "stay put" is that a child ought not to be deprived of an education while his parents are appealing a decision of the public schools to place him somewhere else. Daniel was supposed to begin receiving services from CSAAC, because that is what he had been receiving before the dispute. CSAAC did not provide any services for Daniel.

The case of Daniel Wagner v. Montgomery County Public Schools began before an administrative judge in the county on February 14, 2002. Twenty-six hundred pages of

testimony have been given by the Wagners and by past and present CSAAC personnel, and others. The school district argued, as CSAAC had in the October 3rd letter, that the Wagners had been unable to handle two highly demanding home-based A.B.A. programs. At the same time, it argued that the views in the letter had not influenced its behavior at the I.E.P. meeting--a contention the judge found unconvincing. According to law, the Wagners should have been informed of the letter because the school district had based its placement decision on information in the letter, without giving the Wagners a chance to answer CSAAC's charges. The Wagners maintain that they did provide the required hours of weekly therapy, and denied CSAAC's other charges.

Because CSAAC never resumed the court-ordered services to Daniel, the Wagners also went to federal district court, where, in April of 2002, Judge Deborah K. Chasanow ruled that Montgomery County must provide Daniel with a "stay put" that did not involve CSAAC, because CSAAC had "utterly failed to recognize their obligations to Daniel." In June, Judge Chasanow ruled that the LIFE program would be Daniel's "stay put." On June 20th, Daniel began a LIFE home program. Grace had entered a LIFE program two months earlier.

Daniel's progress advanced more rapidly under LIFE's consultant than it had under CSAAC's staff, and so did Grace's. In the fall of 2002, the Wagners hired Bonnie Dayhoff, who had quit the job she had taken after leaving CSAAC, because she preferred doing A.B.A. therapy. They also hired a woman named Noel Bingham to work with their children forty hours a week. Noel, a recent graduate of Catholic University, had met the Wagners when she was working part-time for CSAAC in 2001.

On September 9, 2002, Daniel went to kindergarten at Potomac Elementary School. While he was at school, the vice-principal telephoned Regina to say that Daniel would not be allowed to attend the school again. The district still insisted on Maryvale. The Wagners' attorney called Judge Chasanow and requested an emergency hearing by telephone. Judge Chasanow ruled that Daniel must be allowed to attend Potomac Elementary School. Daniel returned to kindergarten on September 17th. Grace began her second year of nursery school at Mill Creek. Noel or Bonnie usually gave Daniel and Grace therapy in the morning and shadowed the children in the afternoon. During his first four days at Potomac Elementary School, Daniel required constant prompting from Noel or Bonnie: to hang up his backpack; to greet his teacher, Kit Noonan; to initiate contact with other children; to "choral-count" how many students were present. Still, in early October, when someone from the school district asked Ms. Noonan to prepare a report on the suitability of Daniel's placement in her class, she wrote that he was adjusting well. At first, he had had to leave the room a couple of times a day, in order to "get himself together"; now it was necessary about once a week. Although he wasn't yet ready to follow through on multi-step directions, she could work with Daniel after she got the other students going. Daniel "is responsive to me, sweet, and kind. I enjoy working with Daniel. I do not think I could manage all 18 students without the help of Daniel's shadow." Ms. Noonan told the Wagners that she was not permitted to give Daniel a standard report card. It took the Wagners two and a half months to obtain a copy of Ms. Noonan's report on their son from the school district.

Meanwhile, Daniel learned the names of all his classmates, played "hot potato" with them, and when he was asked by another child to "Sit down next to me" he did. He was invited to a birthday party for the first time. The party took place at Jeepers!, a local chain of party and play establishments designed for young children. Daniel played on the bumper cars and the roller coaster, took his turn hitting a pinata, and, according to the birthday child's mother, enjoyed himself.

On November 2nd, the Montgomery County administrative-law judge ruled on the due-process hearing that had begun nine months earlier, in which the Wagners asked that Montgomery County be required to pay for the LIFE program. "Their challenge to the Maryvale placement was not the typical scenario, where the school offers one program and the parents prefer a different program that they think is better for their child," Kerry Edwards, the Wagners' lawyer, says. "The school district itself determined that Daniel's special-education needs require more intensive services than can be provided in a special-education classroom like Maryvale, and authorized funding for a home-based A.B.A. therapy program for the 2000-01 school year, and again for 2001-02. When the school district's contractor, CSAAC, stopped providing services to Daniel in November of 2001, the district, instead of simply approving an alternate provider to continue the A.B.A. program that Daniel's intensive needs required, placed him into the Maryvale special-education classroom in the middle of the school year without any transition."

The judge, however, wrote that he had been impressed by testimony from the school district's autism specialists as to Maryvale's competence to administer A.B.A., and, following the precedent set by the Supreme Court in 1982, he ruled, "There is no requirement that the state provide a child with the best education--public or private--that money can buy, nor is the state required to maximize the potential of the student. All that is required is that the disabled child benefit educationally from the program." He did not consider the question of why the school district had ended Daniel's home program, and made no determination regarding the merits of the CSAAC accusations against the Wagners. The case is now under appeal.

FLIGHT

In mid-December, after Montgomery County had failed to reimburse LIFE for six months, LIFE stopped sending its consultant to the Wagners' house and to Daniel's school. On January 15, 2003, an I.E.P meeting was held for Daniel that was attended by Scott Wright, the executive director of LIFE. At the meeting, which lasted for eight hours, the county recommended that Daniel be placed in Maryvale. Wright recalls the occasion as one of the most contentious I.E.P. meetings he has ever attended. He didn't think the Wagners would ever be able to get the services their children needed while they were living in Montgomery County.

The toll inflicted on the Wagners by what Katie Wagner calls "too much autism" is in turn reflected on the therapists who work for them. Noel Bingham left the Wagners' employ in late March. After her departure, Bonnie Dayhoff couldn't take both children to school for their afternoon classes, so one of them often missed school. She couldn't give

each child as much therapy as she had when she and Noel were both working full time. Shortly before Mother's Day, the children in Daniel's class at Potomac Elementary School made picture frames out of tongue depressors sprinkled with sparkles. All the other children in the class had had their photographs taken. The children were given the photographs to put in the frames; the framed photographs were to be a gift for their mothers on Mother's Day. Daniel was the only child whose photograph had not been taken.

In June, Dan Wagner shadowed Daniel to school for a few days. On June 5th, Dan got into an argument with the principal and the assistant principal about the school's failure to give the Wagners report cards for Daniel. Dan decided that his son would not return to the school for the last two weeks of the term. On June 9th, Dan called Bonnie Dayhoff, who three days earlier had worked with Daniel and Grace until eleven o'clock at night, and informed her that her services would no longer be needed. Bonnie has telephoned the Wagners many times, but they haven't returned her calls. She feels hurt by the way the family terminated her services.

Sometime that spring, the Wagners, without telling anyone, had decided to leave Maryland and move to New Jersey. "Once you litigate against Montgomery County, you have a black mark against you," Regina said recently. "I was afraid that the county would soon start trying to send Grace to Maryvale." Regina was also concerned about George, who appeared to be speech-delayed. "The county claims I can't handle two A.B.A. programs. They would never give me a third. We need to start over somewhere else. I've got to believe there are school districts that will be more willing to fund A.B.A. programs and to enable me to mainstream Daniel." Dan would commute to his job in Washington, and continue working the double and triple shifts that provided overtime pay.

One hot and humid Saturday before they departed, Dan Wagner worked the day shift and returned home around four o'clock. The family climbed into their white van and Dan drove to a Best Buy. The computer mouse was broken and Daniel was edgy--he fidgeted, he wailed, he kept repeating the words "I want computer, please" in a robotic tone. Katie wanted some new DVDs, and Daniel wanted a particular DVD about dinosaurs. In May, Daniel had broken a lock to gain entry to the Wagners' hundreds of DVDs and had stacked them up, scratching many. At Best Buy, Dan selected a mouse. Daniel was upset that the dinosaur DVD wasn't in stock, but he didn't throw himself down on the floor, as he would have several years earlier. Katie easily persuaded her parents to buy two Kimba videos for her. She asked Grace to please, please, pretty please request a Goofy DVD, which Katie wanted. Grace didn't appear to understand what Katie was saying and gave Goofy only a sidelong glance. Grace was wearing her favorite article of clothing--a bathing suit. Her face and back were reddened and purpled with her mother's lipstick and Chanel eyeshadow: Grace had discovered where they were that morning and had applied them liberally. She tilted her head and smiled a slightly crooked smile at her reflection in the screens of a number of television sets that were tuned to the same program, and from time to time she recited passages from songs and nursery rhymes. On the way home, the Wagners played a Beatrix Potter CD. "Sixteen, please," Daniel repeated, in an increasingly distressed monotone. "He knows the numbers of his favorite tracks on most

of our CDs," Regina explained. The sixteenth track was replayed. Back in the house, Dan connected the new mouse for Daniel, who was soon upstairs using the computer quietly. George had napped through the Best Buy outing and remained asleep. Katie began to watch the first of the Kimba DVDs. Grace watched, wandered off, and returned.

The Wagners' house was uncharacteristically tidy, because they would have to sell it in order to buy one in New Jersey. There were a few plastic toys on the floor, but no children's wet or dirty clothes, no discarded hamburger buns, chips, or juice boxes. The dining room was bare, with only a table and chairs in its center. Many of the family's belongings were in large storage containers in the yard. Grace's therapy room was almost empty.

There were still a few of Daniel's and Grace's toys in Daniel's therapy room, but the floor was covered with packed boxes. Grace had opened a couple of boxes containing bottles of bubbles, spilling the sticky liquid, so some things had to be thrown out and some boxes had to be repacked.

After taking a nap, Dan began to repaint Daniel's bedroom, while Regina prepared dinner. She put a strip steak for Katie and cheeseburgers for herself and Dan and Grace into a frying pan. "Katie does without so much that she would have if she had normal siblings, so she's the only one who gets a steak," Regina said. She heated about twenty chicken nuggets and two types of potatoes. The family sits down to dinner together on Thanksgiving, but on this Saturday, as on virtually all other nights, they ate separately. Regina and Dan had cheeseburgers and potatoes in Daniel's room while Dan continued to paint. Katie ate part of her steak in the living room in front of the television set. She left most of it on the plate, because she thought it was too gristly. Grace ate her cheeseburger at the dining-room table, and from time to time nibbled on green Play-Doh from its container and applied another color to her face. Regina had put a plate of cheese and crackers on the table. George climbed up and ate all the crackers, one at a time. When the family orders take-out Chinese, he eats eggrolls and moo-shu pork. Daniel eats only foods that are tan or yellow. Regina handed him a plate with all the chicken nuggets, and he went upstairs to eat them at the computer.

For one whole year, Regina had prepared casein-free, wheat-free food, because she had heard that such a diet was beneficial to autistic children. She made healthful chicken nuggets from scratch, but Daniel would not eat them, even when they were presented to him in a McDonald's box. Regina is prone to migraine headaches. She didn't have a migraine during the casein- and wheat-free year, but the diet didn't make the children less autistic, so she went back to cooking as she had always done.

When Daniel came downstairs, he was wearing a T-shirt but no boxer shorts: he finds clothes uncomfortable and strips as soon as he gets home. He saw Katie watching the first Kimba DVD. "I want Kimba, please," he said. "No thank you" was his response to her offers of other DVDs. Eventually, Regina came back downstairs. She wanted to check her email and told Daniel he could then go online. "I want Teletubbies dot com, please," he said. Once there, he clicked onto his favorite link--the Teletubbies' animal parade--and replayed a snippet two dozen times. He went back downstairs and asked Katie for "Kimba, please." Katie had finished the first Kimba, so she handed him the DVD and began to watch the second. When Regina went upstairs a few minutes later, she found

Daniel naked and in obvious need of the toilet: she got him to the bathroom just in time. Grace took a bath and went to bed first. The family had slept late that morning, and the other children weren't asleep until after midnight. Regina put a video called "Nighty Night" on the living-room television set. "It features classical music and is supposed to get kids to sleep in twenty minutes," she said. George yelled, "Five, four, three, two, one!" at the top of his voice, and shrieked a few times, but was comforted when Regina said "Oh, George" to him in a soothing tone for perhaps the fiftieth time that day, and he nodded off. She carried him up to his crib. Daniel fell asleep suddenly on the living-room floor. When Regina woke him up, he walked quietly up the stairs with her and got into his bed. Before she went to sleep, early on Sunday morning, she read a few pages of a magazine. At the end of each day, she tries to remove herself from "the reality of too much autism."

The Wagners moved in late August. They bought a nineteenth-century house with five bedrooms. In the Potomac house, Katie had to sleep on the living-room sofa. Katie now has a bedroom on the third floor; she reaches it by way of her own staircase and can lock the door. Her Beanie Babies and books and Magic Markers are now out in the open, safe from the younger kids. The town to which the Wagners moved is more amenable to funding A.B.A. programs than Montgomery County. In some towns in New Jersey, decisions are made by individual townships, rather than by counties, and autistic children have a better chance at mainstreaming than in larger jurisdictions. Property taxes are considerably higher. According to the Times, even in New Jersey, where annual costs for the state's two hundred and eighteen thousand special-education students are at least twenty thousand dollars a year (the cost for ordinary students is about ten thousand), school boards and administrators "are increasingly raising a once taboo subject: saving money in special education by saying no to parents who demand a private placement and offering them special in-house programs" like the one Montgomery County offers at Maryvale.

So far, the I.E.P. meetings that the Wagners have attended have been cordial. Both Daniel and Grace have been getting their forty hours a week of A.B.A. and shadowing. Daniel has been attending first grade with his shadow since early September. He leaves school before the end of the day, because he is not ready for subjects like social studies, and because he needs time for A.B.A. He is still robotic. His medication has been changed from Risperdal to Abilify, a newer drug. The transition has been more difficult for Grace, who didn't start attending kindergarten with one of her therapy aides until the end of October and is reluctant to sleep in her new bedroom, preferring to sleep on the sectional sofa that was her perch in Potomac. Grace has a good memory. When she sees someone for the first time in months, she greets the person by name, and gives her a hug and a kiss. George, who is about to turn three, has been diagnosed with P.D.D.-N.O.S.

The litigation in Montgomery County is ongoing. "We moved away, but maybe we can keep some other family from being run out of town," Dan says. Although it has taken a toll on the family, Regina and Dan believe that having Daniel and Grace in a regular school has been worth the struggle; if they hadn't litigated to get Daniel into kindergarten the previous year, he would have fallen further behind. There is no evidence in the

literature to suggest that having one or two autistic children per classroom is detrimental to normal children, and many people believe that exposure to children who are autistic teaches tolerance.

Daniel recently received his first report card, and his parents are proud. "Having Daniel get a report card is a reward for all his hard work," Regina says. "It's a big deal. What an achievement for a child with his disability. And his teacher gave him a part in the Thanksgiving play. He's going to recite a poem."

The school doesn't give letter grades. Instead, report cards rank students' work as either Proficient, Making Progress, or Needs Reinforcement. Daniel got some good marks, but he received a Needs Reinforcement in "Orally responding to questions about stories." The Wagners and the therapy aides are working with him on that skill. "We just started teaching him `why,'" Regina says. "We tell him, `Touch the sky.' He says, `No, I can't.' We ask him, `Why?' He answers, `Because it's too high.' That's the `Why Because' program. We introduced it a week ago."

Clinical Implications of Ego Psychology

David Rapaport (1954)

I assume that in talking about ego psychology here I can take it for granted that it is familiar to most of you and therefore I will discuss mainly some clinical implications. However, I would like to spend the first third of my presentation on certain concepts of ego psychology, so that I can afterward talk more easily about things clinically important. What is ego psychology? In general, it is a term used in contrast to and complementary to id psychology. The great discovery of psychoanalysis was a thoroughgoing psychic determinism in all behavior. This consideration of motivation had a huge impact upon psychiatry, psychology, and clinical psychology. In the course of the search for the motivation of behavior, we forgot or neglected for a long time our interest in matters not motivational. In the amoeba, whatever motivating state exists is going to create pseudopods. It will reach out, pull in, etc. But it has a nucleus which does not change with motivation. Human behavior has many features comparable to the nucleus of the amoeba: for instance, what we today call inborn ego apparatuses, namely, motility, perception, memory, and the threshold apparatuses. The latter define the point at which the organism is ready to discharge a certain tension. My first point, then, is that ego psychology deals with the apparatuses we use in reaching the goal of a motivation. However, this is not all ego psychology has come to represent.

Again we have to look back on what we have learned from psychoanalysis and what has become commonplace in psychiatry, psychology, etc.; namely, if a human being behaved in a certain way we have been looking first of all for his motivation and have come to disregard the fact that behavior is determined not only by unconscious motivation but also certain reality conditions. For example, a cigar can be just a cigar and not primarily a penis symbol. We are infected with a kind of thinking: something peculiar a patient does is immediately interpreted in terms of dynamics, to the neglect of environmental conditions. It is a difficult job to create concepts which take account both of intrapsychological motivations and reality adaptation. How difficult this is will be

clear to you if you consider for a moment the aims of treatment. What is the aim of psychological treatment? Is it to liberate an individual from his defenses? We all would agree that liberation from crippling defenses is the aim of our work. In the meantime, however, there is also something we keep in the back of our minds, and some of us may even keep it in the foreground: the patient needs to find his place in society and lead a useful, productive life. What is our goal? Is it liberation of the person or is it fitting him into something? This is a kind of choice which probably should not be made by us. Maybe it could be compared with the choice of the young Hungarian nobleman who was waiting for his wife to deliver. As he was waiting the nurse came and brought out triplets. He put his finger to his nose, pondered, and finally said, pointing to the one in the center, "I'll choose this one." Should we lay down the law and say to the patient, "You've got to quit doing rebellious things and be a good boy?" Maybe the patient's only way to survive is to be rebellious and the only way he can serve as a useful person is to be a very sick, reckless person and the way in which to give him help is to help him feel reasonably comfortable as a reckless, rebellious person. Once you start out that way you are all involved in the problem of social adaptation the way Adler, Horney, etc., were and the danger is that you may begin to forget the intrapsychic determination. The balance between understanding unconscious motivation and finding the social niche into which a person fits is not essentially a paradox, but people have chosen to do either one or the other instead of trying, as present psychoanalysis tries, to reach a synthesis. The problem of adaptation versus the problem of freedom from crippling defenses is a problem of ego psychology.

I would now like to proceed to some points in ego psychology which have direct clinical relevance. I will first present a concept termed by Hartmann "preparedness for an average expectable environment" and labeled "mutuality" by Erikson. Its significance and clinical relevance is in shedding new light on the mother-child relationship. What is preparedness for an average expectable environment? Erikson and Hartmann attempt to collate evidence that the human infant is born so that it is prepared to be able to survive in an average expectable environment. That is, the mother has a receiving apparatus for the signals of the infant; the infant has a receiving apparatus for certain nonverbal signals of the mother; and from the beginning on there exists a mutual relationship by which the infant steers the mother and the mother steers the infant. Inherent in this concept is the idea that it speaks of an evolutionary product, of one which is guaranteed by evolution for this creature, man, who has the longest dependency period of all creatures. His helplessness has evolutionary advantages only because of certain mutual steering devices of mother and child by which this helplessness can be managed. This might seem to be a very abstract concept. What does it have to do with the clinic? You all, I am sure, have heard about the "schizophrenogenic mother," the mother who makes her child schizophrenic. Such concepts as those of Erikson and Hartmann demonstrate that this is an inadequate concept. This is important because if the concept of the schizophrenogenic mother is canceled out, then our outlook on the illness changes and therapeutic work becomes somewhat more hopeful. I would like to try to show you in what sense the concept of mutuality militates against the concept of the "schizophrenogenic mother." If the relationship is mutual, then the relationship between the mother and child is relative and neither party can be blamed. Once you start with this assumption, you hit on clinical evidence which was not noticed around Washington, where the concept of the

schizophrenogenic mother was born. The infant who later becomes schizophrenic often displays very early a certain lack of response to signals. Clinically we see these children later as borderline schizophrenics who do not give you any indication of whether they like what you are doing or not. In that type of case, which is called the autistic or schizophrenic child, there is apparently from the very beginning some kind of lack of mutuality, lack of signal giving and receiving. This deficiency then comes into the hands of a mother who herself may have difficulties of some sort. She reacts to his deficit with rejection and guilt, and thereby perpetuates it. It is easy to forget that it is partly the child who made the mother like that and that it is hard to be a mother to such a child. This is an ego-psychological issue for three different reasons: (1) It deals with the apparatuses, namely, the threshold for signal giving and receiving. (2) It deals with the very first adaptation, and it deals with preadaptation on which all other adaptations are built. (3) As the therapist, you will deal with these patients not by approaching this type of problem in terms of motivation but in terms of the problem of re-establishing a human relationship in which the lack of ability to give signals is going to be re-encountered and re-evaluated, in which the desire to give adequate signals may arise for the first time in such a patient's life. No interpretations are going to bridge the original gap in equipment, yet this gap is not irremediable. It certainly is remediable with schizophrenics who before they became schizophrenic had some achievements, and it is remediable even in some autistic children who never developed the requisite thresholds and signals. All of us as children had, in some respects, weak signals. Our thresholds varied greatly, and our mothers, having met our deficiencies, helped us slowly to develop adequate thresholds and helped us to develop a mutual relationship, out of which later in life trust could develop instead of leaving us in a condition of lack of mutuality, the hotbed of mistrust as a fundamental ego tendency. Even before Hartmann and Erikson, Paul Schilder had pointed out that man does not "become socialized" from being first an "egotistic" little wild animal, as the period of enlightenment and even psychoanalysis thought. Schilder asserted that man is a social being from the word go. This is something important to keep in mind when working with a schizophrenic, because if you had to make him into a social being by your work with him, at some point you would give up, unless your megalomaniac ideas about yourself are unlimited. Unless you know that he has it in him and you need only to discover and to liberate it, the courage which is necessary to stick it out with a schizophrenic cannot be had. Even this fundamental, primitive, and really remote ego-psychological concept thus has considerable clinical relevance.

Now I would like to pick up another concept, Freud's definition of the ego in *The Ego and the Id* (1923). The first definition that Freud gave of the ego, and the most general one, was that the ego is "a cohesive, organization of mental processes" (1923, p. 15). This definition distinguishes the ego from the id, which is not a cohesive organization; drives coexist in it side by side. The superego is not a cohesive organization either. It collaborates with the id in what it is intending and punishes the ego for its intentions. Maybe you know the story about the little boy going toward the candy jar. Before he got there, there was a great clap of thunder and the boy looked up and said, "Good God, isn't one even permitted to think of it?" I suggest that the superego does that in an even more extreme way. The boy would not even have to be sure he was going after the candy; just some slight yearnings and punishment would already be there. On the other hand, there is a fluid transition between the ego and the superego in what we call the ego ideal. So the

superego is not cohesive either. This definition thus counterdistinguishes the ego from the other structures in the psychic apparatus. Is this all it is supposed to do for us? No, this definition implies quite a bit more. If it is a cohesive organization, then it should be capable of keeping various of its aspects coordinated. It indeed does so, through what we call the synthetic function of the ego. What is this synthetic function and what is its clinical relevance? I will try to give an example. Suppose that among the few ideas I have introduced so far, one is relatively new to some of you here. Let us assume that I tried to present that relatively new idea so that it should not come out of the clear blue sky. But even then the connections in which I presented it were only in my mind and did not yet have a place in your own thought organization. After a while, however, if you are struck by one such idea, it will lodge safely and securely among other ideas you have in your mind. It is not my job to put it in place in your mind. If you had to place it by an effort, listening would be a most difficult job. Actually, neither my nor your special effort places a new idea in its place in your thought organization. It is done quasi-automatically by the synthetic function. The new idea is put together with old ideas rather automatically. True, we can do a deliberate and effortful job of thinking at times, but most of us, most of the time, rely on the synthetic function of the ego in general, and in particular on that aspect of this function which works in thought organization to put things together for us. We say it "fell into place" and we understood. This may not happen while we listen, but maybe not until later; the beginnings, however, are there. The speaker tries to bring the material in and move it into position for that function to grab it and put it into place. What is the clinical relevance of this? First of all, it is relevant in relation to the long-standing discussion of the dynamics of the effect of our most important therapeutic tool, namely interpretation. How does it help? An interpretation brings into a new relationship the existing conflicts and defenses and then leaves it to the synthetic function of the ego to do its job on it. If the interpretation did not take, you work it through, over and over again, applying it with the patient to ever new areas. It is like a big stone which is lodged heavily in a stream. You are trying to get the dirt from around it and start rolling it, leaving it to the stream to lodge it in a place where it will not be an obstacle but an advantage. With schizophrenics we know that unless we bring about a situation where synthetic forces can work again, the job cannot be done, because it cannot be done by the therapist alone. To achieve this is often not a job of interpretation but a job of a different sort, that of creating a relationship that can free sufficient energies with which synthetic forces can begin to work. A knowledge that you can rely on the synthetic forces to come into play sooner or later is actually what can keep you working at psychotherapy with the schizophrenic or even with the neurotic.

I would like to turn now to a third problem, that of autonomy. What is autonomy? First of all, it means that the sensory apparatuses, the motor apparatuses, the memory apparatuses, and the threshold apparatuses are not born out of conflict. These are ego apparatuses, the most important use of which is in searching for the drive object in reality. If one assumes that ego apparatuses are, from the beginning, part of the psychic organization, then the old psychoanalytic conception that ego is born out of id does not hold up. It becomes necessary to assume, as Hartmann indeed does, that the ego and the id both emerge by differentiation from a common undifferentiated matrix. These primary ego apparatuses pre-exist conflict and enter the conflict as independent factors. Although they may be drawn into conflict, they are autonomous from the beginning. But there is

also another type of autonomy: if, in the course of an instinctual conflict, new structures, for example defenses, are created, these defenses may persist after the conflict that gave rise to them has long since subsided. They become independent from the original conflict and become secondarily autonomous apparatuses. They become ready-made tools to cope with all kinds of tasks of executive, conflictual, or adaptive nature. Language is a good example. There may be a question about any autonomous apparatus or ready-made tool of behavior, about whether it is a primary, ready-made tool pre-existing the differentiation of ego and id, or is only acquired in the course of the battle of life and then becomes detached from its instinctual, conflictual source of origin.

There is one specific issue of autonomy on which I would like to dwell further. Suppose a person developed a certain defense; for example he cannot show, or even experience, his aggressions. He leans over backward and is oversweet, with a great inclination to be very helpful to all comers. "No, I am not aggressive at all, I am most accommodating." He aims to please. Suppose you analyze that person. Does it mean this person then must quit being a helpful and serviceable human being and become an aggressive bastard? Is this an inescapable implication of therapy? Luckily, human nature is not that way. An autonomy once achieved survives. That is why Koestler is wrong when, in his *Arrival and Departure*, he has his hero arrive on an island as an honest radical and depart from it after being analyzed as a smug Philistine. Man does not happen to be made that way. What is the clinical relevance of this? It is that in a schizophrenic the structures that have been built up in the course of the development of his personality have not been obliterated by his illness. They go into disuse, they become unreachable—just as your sense of humor may be lost for a time when you are in a disagreeable position but returns to you later—but they are not destroyed. Sometimes when we are with a bore, we find ourselves to be just as big a bore as our counterpart. You know the situation, don't you? Does it mean that we have lost all the structure we have achieved, all the knowledge, all the interest? We do not lose them, they have just become unusable. The same for the schizophrenic patient: his structures just become unavailable to him and your job as the therapist is to help rediscover them. This is what we help them to get at and not something strange that belongs to somebody else. Dynamically as well as therapeutically, this autonomy is of the greatest significance. It is easy to see what is wrong in our patients but a lot more difficult to see what is right, what is preserved. To learn to look for what is preserved is of great importance and is the point driven home to us by the conception of autonomy: whatever was once achieved is never lost. Any achievement noted anywhere in the case history, any valid perception, any single bit of knowledge, any differentiated feeling, any success, indicate to us that somewhere there was once something that can serve again as a nucleus of a new departure, providing we can reach it, free the synthetic forces, and progress from there to further self-discoveries of the best in the patient's essential social nature. This is the point no patient fully expects and that many of us do not fully appreciate in ourselves: there are persevering secondary autonomous structures and there is a basic sociability, and there are primary autonomous ego apparatuses even in our sickest patients.

The last point I would like to dwell on is the issue of identity. I have indicated already that the social adaptation that man makes is outside of our ken while we are hunting only for motivations. The explanation of social adaptation has not been part of our psychoanalytic teachings for a long while. While Adler, Kardiner, Fromm, Horney, and

Sullivan were very interested in this adaptation problem, they forgot to deal with the problem of unconscious motivation. The problem arises: What kind of concept can one develop by which both adaptation and unconscious motivation can be dealt with simultaneously? In order to be able to talk about concepts I will dwell on Erikson's concept of identity. Let us assume that to begin with there is a loose ego organization holding together the various thresholds and the apparatuses of motility, perception, memory, etc. As instinctual development progresses, we reach the point where this ego organization has to cope with thoughts, approvals, disapprovals, etc. All of these will impinge on this ego organization and alter it. There will remain a continuity between the original, loose ego organization and the later, more differentiated ones. For this continuity we do not have an agreed term. Sullivan talked about "self." But he used this term for the ego also, while it does not replace the "ego." In the eight stages of man, Erikson attempts to represent both the alterations in ego organization coming about in the course of libido development and the constant features of ego organization and their developmental phases. Hartmann and Loewenstein too speak of autonomous ego development, but Erikson's eight phases are the only consistent attempt to characterize the autonomous course of ego development. To come closer to the clarification of this point, let us turn to another definition Freud gives of the ego in *The Ego and the Id* (1923). According to this definition, the ego is the precipitate of identifications with abandoned objects (p. 36). The point is that in order to sever a relationship to a drive object, we reinstate it in our internal world by identification. Indeed, you know people tell you, "You are just like papa"; you put your coat on the way he does, you spit the way he does, etc. But what of the continuity of ego development? Do a person's identifications simply remain a congeries of all these identifications? According to Erikson, in the course of development the synthetic functions of the ego jell all these identifications into one unity. They do not remain disparate parts within us, such as father, grandfather, Uncle Sam, etc.; they are turned into one unity. It is similar to what happens in the course of studies; when you have studied books by various authors your knowledge of psychology is that of the authors, but you are not going to keep each of their thoughts and principles separate very long. Sooner or later they will yield to a unity: your own view of psychology will jell out of them. Similarly the identity jells together all identifications. Erikson was able to demonstrate that in puberty and adolescence there is not only a recrudescence of the various impulses of earlier libido-developmental phases, but also of identifications which were made in the periods in which they were prevalent. They are revived and pass review. Indeed, these and many new identifications which are made are then jelled into one unity: the identity. But these identifications, their social-role, vocational-role, etc., components, acquired skills and expectations, are so jelled into an identity as to guarantee the person a niche in society compatible with his expectations and self-respect. In other words, you find here in Erikson's concept a flowing together of three different conceptual strains. (1) From id psychology the dynamics of identification. (2) From ego psychology the dynamics of synthesis. (3) From social psychology the dynamics of fitting into a social niche, social role. You can see that here we are dealing with concepts integrating these three strains. This I believe is the core and the most lasting merit of Erikson's contribution.

The clinical significance of this is great. In our society, young adulthood is prolonged and reaches well into the 30s, which is later than-to my knowledge-has ever been the case

before in history. Because of this, finding an identity and a definite choice of occupation becomes necessary and is made possible by a social moratorium, that is, by society's acceptance of experimentation. This does not explain the dynamics and I am not endeavoring to go into that now. We do know, however, that what the adolescent and young adult are struggling for is to unify identifications and a lot of roles so as to find the niche that fits them, and thus to gain recognition which will guarantee self-respect. Our first rule in therapy is to interpret what is readily available. This struggle for identity and role definition is usually the most obvious and readily available material in young adulthood.

REFERENCE

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