

Why This Manual?

Catherine Maurice

The phone rings. "Hello?" The caller might be the mother of a child newly diagnosed with autism. Sometimes she is nervous, almost breathless with anxiety. She has many questions—questions that I have heard over and over again.

"I want to get my little boy into behavioral therapy. How do I start? Where can I find trained help?"

"How can I pay for this therapy? How much does it cost?"

"My little girl is 6 years old. Is it too late to start a behavioral program?"

"My daughter is only 2. I'm worried about such an intensive level of therapy."

"My son does smile and look at me. Will behavioral therapy destroy his spirit?"

"I want to do a behavioral program, but I want to combine it with occupational therapy (or speech therapy or vitamin therapy, etc.). Can I combine several different approaches?"

I could go on and on. Over the past 2 years, the questions are always the same, and they are all urgent.

Parents call because I wrote a book about our own family's struggle with autism (Maurice, 1993). Two of our children, first our daughter and then our younger son, had been diagnosed with the condition, both around the age of 2. In the beginning, I had the good fortune to hear about an article describing the remarkable results obtained by Dr. O. Ivar Lovaas, of the University of California at Los Angeles (Chance, 1987). Dr. Lovaas, we learned, had achieved unprecedented results for young children with autism by treating them in an intensive behavioral program that typically entailed up to 40 hours a week of individualized instruction.

From the article, I formed a very hazy understanding of the approach Dr. Lovaas had employed with the children. I understood it to be a form of "behavior modification," and at the time, that term conveyed to me a mechanistic, forceful method of training dogs and seals and even rodents—nothing to which any loving parent would ever subject a *child*. I was encouraged by Dr. Lovaas's positive results, but dismayed by any thought of using behavior modification on my 2-year-old.

I was disabused of these prejudices and preconceptions when, out of sheer desperation, I agreed to let a young woman named Bridget Taylor show me what this type of teaching entailed, for a strictly controlled trial period in my home ("No aversives! This is my house!"). Bridget was able to demonstrate, in a very short time, how effective an approach based on the principles of Applied Behavior Analysis can be for children with autism. Under her tutelage, my daughter not only began to learn how to communicate, but started to make eye contact, to pay attention to us and to the world around her. I remember the day that I first began to believe I had been wrong about behavioral intervention. It was the day that my Anne-Marie walked to the door on Bridget's arrival, looked up into her eyes, and smiled.

Thank God I was able to trust my daughter's smiling eyes, and not my own preconceptions about this type of intervention. Under the guidance of Bridget and several other therapists, we were able to bring first our daughter and then later our son to health (Perry, Cohen, & DeCarlo, 1995).

But our experience left me frustrated, indeed appalled, by the continuing ignorance about behavioral intervention on the part of various "autism experts," many of whom had not kept abreast of the professional literature. I decided to write about my family's experience. In June 1993, my book was published, and then the stream of letters and phone calls began.

I knew from reading these letters and listening to these phone calls, and from my own experience, that parents (and other people who care about our children) had a vital need for credible information. When we are faced with a diagnosis of autism, we need to know how to sift through various recommendations, how to discriminate and judge among our options. We need factual information, preferably science-based and time-tested. We don't need everyone's opinion; we need objective data with the highest possible degree of reliability. We need guidance that is truly well-founded and objectively validated.

I knew that I could offer parents some understanding, for I had seen that our experience with diagnosis, sorrow, fear, miracle cures, inflated promises, false expertise, and uncertainty was not unique. Indeed,

many of the letters I received included very similar remarks: "You have written our story. . . . You could have been describing what we went through. . . . I couldn't believe how similar our experience was to yours." It seemed that the pain and frustration that our family had known was shared by many families.

All parents who receive word that there is something wrong with their child experience fear and grief, but a diagnosis of autism seems commonly to produce an overwhelming degree of devastation and confusion. This is due, in part, to widespread hopelessness and ignorance about the condition. To begin with, most of us have virtually had to hound our pediatricians with our concerns. The pediatrician typically denies or underplays the problem until the child's condition deteriorates to the point where a pediatric neurologist, a psychologist, or a psychiatrist will finally confirm the validity of our fears.

Faced with a diagnosis of autism, which specialists often tell us is irremediable, many of us feel instantly alienated, instantly alone. We have to grieve alone, because usually our friends and families, although often loving and wanting to understand, do not have a clue as to what we're talking about, or they tend to have the same reaction as the pediatrician, minimizing the problem or castigating us as "over-protective" parents.

Why such widespread denial on the part of pediatricians, relatives, and often parents? I don't know. Maybe it has to do with the rarity of the condition, or with the subtle nature of autism's onset in early childhood, or with how normal most children with autism look. Maybe it has to do with the fact that until very recently, autism was considered to entail, in virtually every instance, both a devastating prognosis and life-long permanence.

In any case, once we have received and managed to believe the diagnosis, we are then bombarded with contradictory advice and everyone's pet theory about causation and treatment. Despite strong evidence to the contrary, numerous members of the medical, psychological, and special education professions still see autism as an emotional disorder, caused by some psychological trauma, to be treated appropriately only by gentle understanding of the child and resigned coping on the part of the parents. Support groups and seminars on stress management abound. People who have had no success in actually treating autism spend their time counseling parents, focusing not on what the parents can do for their child, but on how the parents might "change their attitude" toward the condition. Parents are often told that it is not only advisable, but morally imperative to accept their child the way he is. Anything other than

such acceptance is looked upon as a manifestation of a lack of love. Twenty-five years of witnessing the ineffectiveness of this approach still has not dissuaded its advocates.

We who refuse to accept these hand-holding programs thus quickly learn that we have to become overnight experts, doing our own research, evaluating treatment modalities, and finding our own programs or therapists.

Parents thus careen from crisis to crisis. Extraordinary demands are placed on our spiritual, emotional, physical, and financial resources. We must fight on many different fronts while tending to our other children, earning a living, putting meals on the table, and trying not to cry too much in front of people.

And yet, beyond understanding some of what other parents were going through, I could not give them the concrete guidance they sought. Dr. Bernard Rimland, director of the Autism Research Institute in San Diego, had suggested that I write out my responses to some of the most frequent questions and make them available to parents. But I had worked with only two children and seen a few dozen more; I could not assume that such a limited experience would qualify me to know what to do with anyone else's child. I had only the most cursory knowledge of the research literature; I was not trained in scientific research or psychology. The questions parents were asking me were too important to believe that my common sense, my maternal instinct, or my parental perspective could adequately handle them.

Furthermore, I had no desire to join the ranks of people who did present themselves as experts in autism based on their limited personal experience. Of course we who have "been there," whether as parents of people with autism or as individuals diagnosed with autism, have every right to speak or write of our own experiences. But we are not automatically qualified, thereby, to make public pronouncements about causes or treatments, unless we can point to credible scientific research in support of our statements. If I recover from cancer, or if I am the parent of a child who has recovered from cancer, does that entitle me to lecture people, based on my experience alone, on the "best" treatment for cancer? Does that entitle me to sell my services as a cancer-care provider? If I have an M.A., a Ph.D., or an M.D. after my name, does that enable me to claim any particular expertise in autism? Not if the M.A. is in sociology, or the Ph.D. is in Chinese folklore, or the medical degree has never included any study of the current scientific research in autism.

Over the past few years, I have been growing more and more alarmed at the number of people who do make such statements outside of their area of

expertise, and equally alarmed at the extraordinary faith with which parents, many educators and therapists, and members of the media automatically accept those pronouncements.

I had seen the damage wrought by this lack of discrimination and judgment in the world of autism. The history of autism has been dominated by self-appointed authorities who decided, without testing their theories in any controlled fashion, that they understood the genesis of or the optimal treatment for this disorder. Such false authority has taken many forms: Bruno Bettelheim, who had concluded that bad mothers cause autism, reigned unchecked for decades, the strength of his influence resting not on rigorous testing of his psychogenic theory, but on the self-perpetuating, self-reinforcing expertise granted to him by parents and professionals alike. Today, there are still many such authorities whose strength rests on nothing more than their popular following, their longevity in the field, or the emotional seductiveness of their theories and therapies.

But look at the role that we parents play in supporting and endorsing such false expertise. Who keeps the authority figures in authority? Why do we continue to support worthless treatments and self-proclaimed experts in the face of little or no real progress in our children? How did play therapy come to be one of the most often recommended treatment options for so many children with autism (in spite of an apparently complete lack of evidence validating its effectiveness), if not in part through our collusion? Who keeps buying into the latest fad, pouring hundreds of thousands of dollars into therapies that have virtually no published, peer-reviewed, credible support? The history of autism is a history of, as someone once put it, "failed treatments and fads," including everything from psychoanalysis of the child, to psychoanalysis of the mother, to "age reduction," to "patterning," to "total acceptance," to "maternal rebonding," and so on. Sadly enough, however, we parents have supported every one of those failed treatments, those fads, and the authority figures who promoted them.

I think I understand, at least in part, why we keep doing so. When my daughter was diagnosed, I didn't know what the scientific literature said, and the people to whom I initially turned for guidance didn't either. My frantic call to the Autism Society of America yielded an outdated list of reading material that included a book called *Autism: Nightmare Without End*. They also sent a list of the symptoms of autism and a newsletter containing an endless stream of personal opinions written by parents, anecdote after anecdote about untested treatment options, and columns written by people with no apparent scientific credentials.

There was no mention of behavioral intervention, nor any mention of any professional journal that supported behavioral intervention. My pediatrician did not know what to do. Several of the professionals to whom I initially spoke had nothing better to recommend than some counseling for me—"to help you cope with the stress." I was advised by one special education teacher to "take some time for you—maybe get a manicure?" And I found rampant distortion of and denigration of behavioral intervention—by people who had no idea of what such intervention entailed.

In this wasteland of nonhelp, I was open to anyone who would tell me *what to do*. And I was willing to trust anyone who would preach something other than coping. Moreover, all my powers of reason and objectivity were crumbling before the fact that I was losing my child. I was as vulnerable as any parent out there to anyone who would breathe the word *cure*, anyone who would whisper the command "Trust me, and all will be well."

In my case, I believed that holding therapy was my magic bullet. It was championed by people who seemed to have stellar credentials—Nobel prizewinners, no less. (Never mind that their field of study was birds: I was willing to overlook such minor details.) It was based on a theoretical model of biological imprinting that seemed at least somewhat plausible to me. At the time, I thought I could distinguish mumbo-jumbo from good scientific research. Actually, I was fairly ignorant of what constituted truly sound methodology, objective data, and controlled research. Most significantly, however, I needed to believe what my saviors were telling me. I was generally aware of some of holding therapy's flawed premises and dubious proofs, but the strength of my own desire for a cure produced a "willing suspension of disbelief," to borrow a phrase from the literary world.

Since then, I have watched thousands of desperate parents flock to each new "breakthrough" treatment—from swimming with dolphins, to various forms of "insight/bonding/accepting" therapy, to brushing/rocking/stroking therapy, to a new one called "drum therapy," or "rhythmic entrainment," to the scandal of Facilitated Communication, discredited by every single controlled, objective test to which it has been subjected, yet still promising to instantly unlock communication in people with autism. I have heard "consultants" (what's a consultant?) lecture parents on some ill-defined but pervasive cliché called "sensory overload" in autistic people; optometrists hawking \$500 glasses to cure the symptoms of autism; speech therapists making unsupported claims about the curative powers of "auditory retraining"; nutritionists confidently

describing the powers of special diets to heal the “brain pathology” of autism (neurologists should be very glad to hear of how many therapists and parents have confidently identified the brain pathology of autism, something the neurologists have been attempting to do for decades); and New Age gurus telling us that all we have to do is accept the child for who he is, and then he will choose to come out of his autism when he is ready. But one of the scariest things I ever heard in the autism world was a parent, at a large conference in Westchester County, New York, angrily and personally attacking a professional who dared even to raise questions about the scientific foundations of these increasingly outrageous claims. “I am deeply offended!” she shouted at the professional. “You do us a disservice!” In the audience, I thought, “No, she is doing us all a service, after 4 decades of charlatanism, quackery, and nonsense.”

There is almost no limit to what we can be persuaded to believe when our despair, or our hurt, or our fear is combined with a promise of healing and hope. The appeal to the emotions seems far more powerful than the appeal to reason, and there is no dearth of people willing to play to those emotions and eager to adopt that authority role. And parents, just as I did, continue to believe in anyone who can give them comfort, anyone who will give them hope, putting the blinders on when it comes to scrutinizing the credentials of these messiahs, the empirical support for their theories, or the rationality of their statements. One eminent authority in the autism world has asserted that people with autism communicate via extrasensory perception. What’s next? Moon-dust elixir for autism?

What I had to learn about autism was that there are no gurus, no magic bullets. What I learned was that reason and scientific research—cumulative, painstaking, collegial work on the part of many people—has produced the most beneficial results for people with autism. We don’t have a universal cure for autism, but we have an approach that is creating a new future for many people with autism and producing full recovery for some. Today, behavior analysis and its applications have evolved, through countless research projects and controlled studies, into a highly complex and refined corpus of knowledge. I learned that this field is not the province of one or two superstars, but is populated by thousands of researchers and practitioners—people who have dedicated their careers to advancing and refining our knowledge of how children with autism learn, and our understanding of the most effective ways of teaching them. Above all, I learned that we parents, no matter how much we long for a panacea, must allow ourselves to be guided by something other than

our own panicky need for instant answers. We must allow ourselves to be guided by our God-given *reason*, our gift of *logic*, as well as our hope and our prayers and our faith.

Unfortunately, in the quest for rational, authoritative information, the situation for parents still remains highly compromised by the indiscriminate, anything-goes attitude of many individuals and established organizations that are supposed to be helping and guiding us. We should look very skeptically at any publication that advises us to, as one mother paraphrased it, “Throw everything against the wall and see what sticks.” We might do well to look critically at any organization whose publications endorse, advertise, or otherwise even tacitly support every one of those dubious choices and latest miracle cures, while apparently remaining ignorant of what is appearing in the professional, science-based literature. The harm that is caused by such a politically correct, let’s-not-offend-anyone attitude is incalculable. Money, energy, opportunities, and precious time go down the drain when parents are encouraged to pursue anything and everything, whether or not it is backed by reliable evidence.

Much of this indiscriminate attitude is dressed up in an appealing message about the necessity of remaining open-minded to different treatments. Of course we should remain open to all promising avenues of research and treatment, but there is a difference between a promising area of inquiry and the myriad treatments that continue to be endorsed in spite of weak or absent supportive data. If that history of “failed treatments and fads” has taught us anything, it is that we either turn to interventions whose credibility rests on something other than opinion, anecdote, or emotional need, or we will repeat this history *ad infinitum*. The fact that “each child is different,” so often preached by the supporters of dubious therapies, is no justification for letting our children be used as guinea pigs for every new breakthrough that hits the autism world.

In short, it had become apparent to me and to several researchers and psychologists with whom I was discussing these issues, that the autism world continued to be dominated by an astonishing amount of misinformation, false expertise, and ferocious ideological warfare. It was equally apparent, given the growing research findings about the value of early intervention, that there was a critical need for parents to gain access to science-based, accurate information about such intervention. I believed that we had enough books and articles about coping with the emotional turmoil of autism, and we had nowhere near enough books addressing the issue of effective early intervention for autism and current research findings.

In early 1994, I began to search for the people willing and able to contribute to such a book. Fortunately, I have come to know and trust some researchers and practicing psychologists who believe in good science, not in the superiority of their own insights or in the “try anything” approach. I turned to Dr. Stephen Luce, vice president of program operations at Bancroft, Inc., a large rehabilitative facility in southern New Jersey, for help in organizing an outreach manual and in contacting key people who could help us out.

Together, we sketched out the backbone of our manual, delineating the major chapter divisions quickly. Our basic strategy was to put ourselves in the shoes of parents, and ask ourselves the key questions that parents ask when they are trying to procure effective treatment for their newly diagnosed child.

I also called Cyndy Kleinfield-Hayes, a parent and strong advocate for children with autism, to ask if she wanted to participate. Not only did she contribute a chapter, she also furnished critical organizational support in the earliest phases of the project, and provided valuable insights from her perspective as a mother still involved in active home programming for her son.

One key decision that Stephen and I made early on, was to concentrate our efforts on the young population. Not that we hold the needs of adolescents or adults to be any less urgent. This is an area of grave concern, and the paucity of quality services for this population remains critical. However, we knew that this manual would become unmanageably broad and diluted if we tried to focus on too many questions and address too many issues. We needed to carve out one discrete area—early behavioral intervention for young children with autism—and try to do as good a job as possible on that already very complex topic.

After we had our basic outline, Steve and I invited a core group of people, whose work we knew, to join the project and contribute a response to some of our questions. We also asked them to suggest others who might want to contribute.

The criteria for inclusion as a contributor were few, but fairly specific. We needed people who were well versed in the field of study called Applied Behavior Analysis. We were seeking people with either significant research experience in this field, or significant clinical experience, and preferably both. We needed people who believed in the value of objective data and results, as opposed to “received wisdom” of any sort. We needed people who understood the importance of a science-based approach to autism treatment, an approach that welcomed professional scrutiny, peer review, objective validation, and the test of time. We needed people with compassion, who understood that the best assistance they

could offer parents was not only understanding and empathy, but concrete information, specific guidelines, and empirical knowledge, the fruit of their experience and study.

At an initial meeting to launch our project in May 1994, we identified and articulated the basic premise that all of us supported and that informs this manual: that Applied Behavior Analysis has been proved, through extensive research over the past half-century, to be the most effective intervention we have for treating people with autism or pervasive developmental disorder. (See Chapter 3 for an overview of this research.)

Another significant point of agreement among us is that, to my knowledge, no contributor thinks of Applied Behavior Analysis as a cure for autism. The term *cure* implies a universality or uniformity of effect that this treatment does not provide. Although several of us have seen children who have recovered normal functioning after behavioral treatment, we have also seen many children who retain some degree of impairment, handicap, or abnormal functioning, even after intensive behavioral intervention. Rate of learning varies under this approach. I, and other parents and professionals who are involved in the field of autism, increasingly believe that the word *autism* is analogous to the word *cancer*. There is one name for many different forms and degrees of severity of the disorder. Some forms are more responsive to treatment than others.

In fact, in my experience in the autism world, it is not the proponents of behavioral intervention who throw around the word *cure*; rather, it is their critics who use the word when they want to contend that the behaviorists are making false promises. From what I have seen, the researchers and clinicians who have been achieving the most exciting results in autism are those who avoid such overly dramatic words and phrases as *cure*, or *breakthrough*, or *emergence of a hidden child*.

Aside from identifying these broad areas of agreement, neither I nor Steve Luce told people what to write or which topic we wanted them to treat. We sent them the list of topics and asked them to select one. (If they had all selected the same topic, we would have had to negotiate, but that did not happen.) Nor did we aim for group agreement on all subjects treated. We wanted contributors to speak for themselves, representing their clinical or research experience, while still remaining faithful to the most current, most data-based, and most generally accepted principles of Applied Behavior Analysis. If there were differences of opinion with respect to particular techniques or procedures, however, we were prepared to include them. Such differences would allow readers

to see that the application of behavior analysis varies from practitioner to practitioner and that, within the general principles of this discipline, what works for one child might not work as well for another. Moreover, many technical aspects of the discipline are still under study, and there is not enough hard data yet to make definitive or absolute statements about particular issues. Two examples that come to mind are the best means of shaping eye contact, and the optimum number of hours per week that a child should be in therapy. Readers will notice that different contributors to this manual may have different opinions on these and other topics, for the simple reason that not enough research has been done to make definitive statements on these issues.

Once the project was launched, it gained momentum quickly, and we were fortunate to win the enthusiastic support of many highly respected researchers, experienced behavior analysts, and skilled therapists. Dr. Luce had agreed to be a coeditor, along with Dr. Gina Green, director of research at the New England Center for Autism. Both, in addition to working in academic and administrative positions, had published extensively, and currently serve on the editorial boards of several scientific journals. Their agreement to coedit the manual made me confident that our work would be subjected to rigorous standards of professional scrutiny.

What *is* Applied Behavior Analysis? In the simplest possible terms (*my* terms, as a mother who learned the approach and applied it to the teaching of her own children), Applied Behavior Analysis involves the breakdown of all skills into small, discrete tasks, taught in a highly structured and hierarchical manner. Central to the successful application of this method is the art of differential reinforcement. That is, the therapist, parent, or caregiver learns how to systematically reward or reinforce desired behaviors, and ignore, redirect, or discourage inappropriate behaviors. Also central to any well-run behavioral program is the therapist's close monitoring of what is working and what is not working. Data on all the child's learning are recorded regularly, and the therapist adjusts the teaching programs and protocol with respect to what the data indicate about the child's progress.

Everything, from learning not to scream and throw tantrums to learning to sleep through the night, to play appropriately with toys, to use communicative language, and to learning age-appropriate social interaction, along with many other skills, can be successfully "shaped," or taught, through this methodology. (I say *can be* taught. Not all children learn at the same rate or with the same degree of suc-

cess as others. The vast majority of children do make progress, but there remains great variability in the long-term outcome for different children. Rate of learning may depend on the inherent potential of the child, on the skill of the teacher, or on other as-yet-unidentified factors.)

Needless to say, a therapist must be keenly aware of an individual child's learning style as well as the latest research on curricula and methodology. The field of Applied Behavior Analysis is evolving constantly, and it is highly probable that some of the material presented in this handbook will soon become dated.

Is autism then "a problem of behavior" as one critic of Applied Behavior Analysis scornfully asked? Obviously, no rational person would consider autism to be a manifestation of poor manners or uncivil behavior. Most researchers, clinicians, and parents now accept the increasing evidence that autism is a neurobiological disorder, and most would like to see a lot more research (that is, a lot more credible research) done on brain functioning in autism. But some of us who espouse this method tend to believe that early structured behavioral intervention may indeed have some rerouting or restructuring effect on a developing nervous system. Moreover, until someone identifies the exact brain pathology operative in autism, all we can usually observe are the external behaviors of people with autism. Those of us who have seen the effectiveness of Applied Behavior Analysis believe that many of those behaviors, ranging from rudimentary self-care tasks to complex skills such as interactive social language, can become permanent parts of a child's repertoire if they are broken down into components that the child can handle, taught well enough, learned early enough, and practiced consistently enough. If one can train the body to run the mile in under four minutes, if one can train the fingers to play a Chopin polonaise, perhaps one can train the developing brain to repair, or compensate for, some circuitry that has begun to go awry.

Perhaps a more direct way to express the effectiveness of behavioral intervention for autism is to say that it seems to help children learn how to learn. (I believe it was Dr. Ivar Lovaas who first used this phrase. I took it up in my book because I found it such an apt description of what Applied Behavior Analysis seems to *do* for children.) With my own children, I found I could use this method to break down learning for them in a way that they could handle, and then fade back and allow them to take over the learning as soon as they were ready. They seemed, at their worst, to be largely indifferent to and unaware of events and phenomena around them. They certainly did not

respond to much of what went on in the environment. But instead of allowing them to sit in a corner and engage in meaningless, repetitive, solitary activity, we began to learn how to help them focus on us, on our words, and on the world around them. We learned, for instance, how to break down language, both receptive and expressive language, into tiny components, and we learned how to actively teach those components to them. Using the methods of prompting, shaping, modeling, and reinforcing that Bridget demonstrated for us, we saw that our children could start assimilating information, and assimilating more and more information as time went on. After a while, we saw that we could begin to progressively fade back on the structure and intensity of the teaching, as they began to take over more and more of the learning themselves. Like other children, they began to spontaneously pick up more and more from the environment, until they were finally learning, without support, from a normal school and home environment.

I hope that readers have gathered by now that behavioral therapy has little to do with merely correcting behavior. It entails a comprehensive program for teaching skills across all domains, from the linguistic, to the cognitive, to the social, to the mundane tasks of getting dressed, brushing one's teeth, and so on. Part of the misinformation that assaults parents consists of the confident assertion by educators, social workers, and others that behavioral therapy is for managing behavior, while special education is for handling academics or language acquisition. Unfortunately, however, many special education programs in this country seem to amount to little more than custodial care for children with autism.

Again, the rate of progress varies under a behavioral approach. On the more positive side, I know of several children who attained normalcy in 2 or 3 years, attend regular classes in regular schools, and have friends. Moreover—and more significantly than my anecdotal information—several data-based reports have appeared indicating that intensive early behavioral intervention can result in hitherto unprecedented outcomes for children with autism and pervasive developmental disorder. Among the most significant of these studies is the 1985 paper by researchers at the Princeton Child Development Institute, who reported that between 40% and 60% (over a certain time interval) of children who had begun treatment with them before reaching the age of 5 improved to the point where they could be enrolled in public schools (Fenske, Zalski, Krantz, & McClannahan, 1985). Subsequently, in 1987, Dr. Ivar Lovaas of UCLA reported that nine of nineteen children who received intensive early behav-

ioral intervention in his treatment program attained normal cognitive and intellectual functioning, and were able to be mainstreamed and to complete first grade with normal peers (Lovaas, 1987). A follow-up report on these best-outcome children, published in the *American Journal on Mental Retardation*, revealed that they had maintained their gains; as young adults, they were apparently indistinguishable from normal peers (McEachin, Smith, & Lovaas, 1993). (Again, see Chapter 3 for an overview and discussion of these and other studies.)

Clearly, Applied Behavior Analysis is not a panacea. Anyone who looks objectively at these studies will understand that even under the very best, most professionally run programs, the majority of children still do not make it to normalcy, recovery, or unsupported inclusion in normal schools. In the few years that I have been involved with autism, I myself have become acquainted with children whose progress has been relatively slow. Steady, but slow. They never stop learning, but it is likely that they will need some form of structured intervention for many years in order to maximize their potential and help them live more fulfilling lives.

Thus, the "perfect" treatment—one that will provide the possibility of a normal life for all children and their families—has yet to be developed. To date, however, scientific research shows that Applied Behavior Analysis has consistently achieved the most significant results for children with autism.

Unfortunately, it is currently very difficult for parents or interested professionals to gain immediate access to the most effective forms of this treatment. At the present time, parents must wait 6 to 9 months to procure even a 2-day workshop from one of the few reputable behavioral programs in this country. The waiting time for actual admission into one of these programs stretches from 1 year to never. The supply of quality services cannot meet the current demand. Trained, qualified professionals who know how to administer this type of treatment are extremely hard to find. There is tremendous interest on the part of parents, professionals, and educators in this therapy, but there is a gap between the professional behavioral community's ability to train new people and the need that exists right now. Moreover, in many communities, it is hard for behavioral therapists to procure endorsement or support from agencies set up to provide services to autistic children, and this too contributes to the scarcity of people willing to devote their careers to this field.

This situation means, among other things, that the field is ripe for abuse, in the sense that a few individuals, knowing the desperation of parents, are

beginning to charge exorbitant fees, thereby effectively denying this therapy to all but the wealthy or the very resourceful. Another type of potential abuse looms in the proliferation of untrained “therapists” who don’t really know what they’re doing, but charge parents for their services anyway.

Knowing the need, we decided to compile as much concrete information as we could for parents and other interested people, in a book which would, when published, be immediately available to anyone. But nothing is simple. Even in the formative stages of the book, I was aware of the potential and actual arguments against it. It is, according to some critics, “irresponsible” and “dangerous” to put this information into “laymen’s” hands. Only trained professionals know how to do this, are qualified to do this. No one should encourage *parents* to do this kind of work with autistic children!

Setting aside the time-worn authoritarianism and paternalism inherent in a few of these objections, parts of this argument are valid. There is danger that a few parents or therapists will take our information too literally, attempt to apply it too rigidly to a child. There is danger of misinterpretation of or overadherence to our sample flowcharts and curricula. There may be misunderstanding of the principles of reinforcement and clinical timing. There is no “recipe” for Applied Behavior Analysis. Each child’s educational programming will be different from another’s. These children may all have autism or pervasive developmental disorder, but they are nonetheless individuals, with varying manifestations of the disorder and varying degrees of severity. Each child brings his or her unique personality into the picture, and we cannot hope to approximate the type of help that a child could receive from a trained person paying attention to his or her specific needs.

This said, however, it is also true that all information about autism has to be adapted to individual children. All concrete recommendations, whether given in a book, a handout, a workshop session, or a school program, must be tested, tried, and modified according to the child’s response. In fact, it is the very nature of Applied Behavior Analysis that procedures be individually tailored to each child. Everyone works by trial and error in a behavioral program, taking information and adapting it according to a child’s changing needs. In the current state of affairs, some people are fortunate to have access to more information than others, so their trials and errors can be better-informed than others. I see no compelling reason to deny parents information because some might misunderstand it, or apply it imperfectly. I see no kindness in “protecting” parents by keeping them ignorant.

Consider this analogy: A woman’s time to give birth has arrived. She is far from any civilized place, where she could be hospitalized and receive all the latest in professional expertise and state-of-the-art delivery care. Two people are arguing over what to do for her.

The first says “I will help her delivery because I have this manual here that gives me a rough idea of how to do this.”

The second says “You can’t deliver babies. You don’t have a medical degree! She should be in a hospital!”

The first responds “Either someone helps her—now—or we will lose both mother and baby.”

Women don’t choose to give birth at inopportune times in remote places. Parents don’t choose to be locked out of the few good programs that treat autistic children. It just happens. I envision this outreach manual as an emergency first-aid kit, a stopgap measure. Time is a crucial factor here. A growing body of evidence supports the value of *early* behavioral intervention for the best outcome. People cannot, and will not, wait years for the behavioral community to slowly respond to their needs—they are fighting for their children.

Obviously, the ideal solution would be for every child, immediately upon diagnosis, to obtain placement in a well-supervised, well-staffed, intensive behavioral program, whether at home or at school. The ideal solution would be to have one very experienced person supervising highly competent therapists, all of whom would have had some research and clinical training at a reputable university, school, or clinic.

Dozens—indeed, hundreds—of people are organizing and working hard, right now, to achieve such an ideal solution. Many of them are parents of newly diagnosed children, who are not only working for their own children, but are passionately concerned about other people’s children as well. These parents have seen the effectiveness of Applied Behavior Analysis, and will not be satisfied until all children have the opportunity to benefit from this treatment.

But grassroots movements take time, and the qualified and caring professionals cannot keep pace with the demands being placed on them. No contributor to this manual would ever claim that this book could *replace* a qualified person or a quality program. We simply hope that it will help people who are struggling now, often without professional guidance, to learn more about early behavioral intervention for autism.

To complicate matters, the very words *quality*, *quality control*, and *qualified* are themselves the subject of controversy and discussion. Many of us would

like to see some form of certification or licensing of applied behavior analysts, some standardization of what *trained* or *qualified* means, at a national level. Unfortunately, capitalizing on the surge of interest in Applied Behavior Analysis for autistic children, a few people are beginning to make exaggerated claims about their level of expertise in this field. Many of us long for some agreed-upon standards that could guide parents in their search for professional assistance. It's bad enough that we don't have enough trained people to go around. The situation becomes even more serious when there are no national criteria and procedures for determining who is competent to deliver behavioral services. Drs. Gerald Shook, Judith Favell, and Jack Scott have written chapters for this manual on these important issues.

No contributor has written on an unimportant issue. Our manual is already very long, and yet there is no chapter I would eliminate. I have already mentioned several of our contributors, and before closing this introductory chapter I want to express my profound gratitude to all the others. Stephen Anderson, Barbara O'Malley Cannon, and Marie Taras have written on "Teaching New Skills to Children with Autism," an overview of some crucial strategies and techniques employed in the field. Andrew Bondy's chapter is designed to assist those who want to advocate for more effective public school education for their children. Elizabeth Braxton, Cyndy Kleinfeld-Hayes, Elizabeth Harrington, and Margaret Harris have all contributed chapters on how autism has affected their children. Gina Green lends credibility to the overused term "empowerment," by providing readers with the conceptual guidelines they need to make their own discriminations and judgments about the host of "options" purported to be effective for autism. In a second chapter, she offers a much-needed overview of what research studies can and cannot presently tell us about early behavioral intervention for autism. Kathleen Dyer and Steve Luce address many of the most common questions that parents ask, and their concerns about behavioral intervention. Ron Huff describes the efforts of a group of Sacramento-based parents to organize and procure funding for their children's behavioral program. Susan Johnson, Linda Meyer, and Bridget Taylor spell out, in very helpful detail, a supported inclusion model utilized at the Alpine Learning Group for progressively integrating a child into a mainstream classroom. Ivar Lovaas shares many valuable observations on staffing and training issues, observations gleaned from a lifetime of study devoted to effective intervention for children with autism. Bridget Taylor and Kelly McDonough

have submitted a gold mine of teaching programs, programs that will surely inspire many more creative ideas in those who read and use them. Robin Parker and Margery Rappaport encourage a dialogue between the disciplines of Applied Behavior Analysis and Speech-Language Pathology, and in so doing, provide parents and therapists with many concrete strategies for facilitating language. Ray Romanczyk elucidates some of the most important components of any effective behavioral program: the different means of analyzing and assessing behavior. Mark Williamson has donated his legal expertise to make the battle for funding easier for other families. And finally, Tristram Smith has furnished readers with a powerful, courageous, and solidly rational assessment of several alternative therapies for autism.

Still, our manual could have been 10 times as long, and we would not have covered everything that needs to be explained and exemplified when discussing early intensive behavioral intervention for children with autism. The topic itself is so important that as the time came to send the manuscript to PRO-ED, I found myself dragging my feet, not pressing quite as hard to get the drafts of chapters back from contributors. The need to get the work out quickly competed with the need to make sure that the work was good, that is, as professional and careful as we could possibly make it. As our publication date draws near now, I am hyperconscious of the manual's imperfections.

However, whenever I wake up at night worrying about all that we could have said and didn't, all that we should have covered but did not have the space for, I take comfort in two thoughts. First, the manual must have some merit, because I had the privilege of working with many of the parents and professionals whose intelligence, compassion, reason, and dedication I admire most in the autism community today. Second, for the mothers and fathers who are currently seeking help for a beloved child, it is better to offer some concrete assistance, however inadequate or incomplete, than to willingly allow their pleas to be met with yet more blame, indifference, misinformation, or silence.

AUTHOR NOTE

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Catherine Maurice
East Hampton, New York
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REFERENCES

- Chance, P. (1987, December). Saving Grace. *Psychology Today*, 42-44.
- Fenske, E. C., Zalenski, S., Krantz, P. J., & McClannahan, L. E. (1985). Age at intervention and treatment outcome for autistic children in a comprehensive intervention program. *Analysis and Intervention in Developmental Disabilities*, 5, 49-58.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- Maurice, C. (1993). *Let me hear your voice: A family's triumph over autism*. New York: Knopf.
- McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, 4, 359-372.
- Perry, R., Cohen, I., & DeCarlo, R. (1995). Case study: Deterioration, autism, and recovery in two siblings. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34, 232-237.

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