

## Early Intensive Behavioral Intervention: Emergence of a Consumer-Driven Service Model

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Parents are becoming influential stimulators and shapers of public policy in regard to educational services for their children. Increasingly, this advocacy has created a controversy about the role of applied behavior analysis as a foundation for early intensive behavioral intervention in autism. Uncertainties exist in policy regarding the role of behavior analysis in early intervention and the capacity of behavior analysis to field a trained work force. Based on contacts with parents of children with autism and information available in a variety of forms on the Internet, there is a rising demand for fundamentally better early intervention services that are available and accessible, provide active intervention, and are based on principles of behavior analysis. Contemporary movements in special and early education, however, appear to be nonconducive to scientifically based treatments, and school districts seem hostile to an increasing role for behavior analysis and to the establishment of services that are responsive to changing parental priorities for the education of their children with autism and related disorders.

*Key words:* parents, advocacy, early intervention, certification, public policy

Over the past several years, there has been rising advocacy by parents for behavioral services for young children with autism and other developmental disabilities (Balcazar, Keys, Bertram, & Rizzo, 1996; Boomer, 1995; Families for Early Autism Treatment of British Columbia, 1996; LRP Publications, 1995, 1996a, 1996b). In particular, parents of children with autism spectrum disorders (e.g., autism; pervasive developmental disorder [PDD], not otherwise specified; Asperger syndrome) have emerged as highly visible advocates for behavior-analytic and related services. They have also promot-

ed development of service settings with boards of directors composed primarily of parents, a pattern reminiscent of the mid-20th century founding of the Association for Retarded Citizens (Scheerenberger, 1983). A great deal of available information regarding parental concerns and interests has not been presented previously in the professional literature (but see Maurice, Green, & Luce, 1996), and is drawn here from conversations with parents during the past several years, as well as from parents who participate on Internet lists and organizations that maintain home pages on the Internet. Some of these lists are confidential, so names will not be provided for all quotations from parents; all quotations, however, are portrayed in context.

In any clinical specialty area or discipline, there are periods of time that are critical because they involve possible changes in public policy with broad impact on services (e.g., Jacobson, 1990). Sometimes professionals characterize such times as paradigm shifts, a time when old knowledge and perspectives are completely overtaken by new perspectives and dismissed

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An earlier version of this article was presented as the presidential address at the annual conference of the New York State Association for Behavior Analysis, Tarrytown, New York, September 1997. Development of this article was supported in part by Independent Living in the Capital District; the perspectives and conclusions presented here do not necessarily reflect those of the sponsoring organization. I thank an anonymous reviewer for providing particularly salient and effective feedback in the revision of this article.

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(e.g., Biklen & Cardinal, 1997). Usually, however, most claims of paradigm shifts lack substantiality when further investigated (Kauffman, 1996; MacMillan, Gresham, & Forness, 1996; Singer & Lalich, 1996). In actual practice, breakthroughs do occur, but they do not occur frequently, and they tend to be based heavily on earlier research or practice demonstrations, not on concepts created *de novo* in the rarefied air of university research (Simpson, 1995). Substantive breakthroughs generally do not necessitate dismissal of previous research, but consolidate research in ways that help us to better understand and use that knowledge in service and education (Gross, Levitt, & Lewis, 1996).

Today we are going through such a period. Thirteen years ago, research findings based on behavior analysis were published by Ivar Lovaas and colleagues at the UCLA Young Autism project. These findings indicated that a significant portion of the preschoolers with autism in their early intensive intervention services had essentially recovered and had achieved typical or average functioning both developmentally and educationally (Lovaas, 1987; Smith, McEachin, & Lovaas, 1993). Other researchers indicated substantial gains intellectually or in specific skills (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Fenske, Zalsenski, Krantz, & McClannahan, 1985), and later research has indicated similar outcomes (Birnbauer & Leach, 1993; Perry, Cohen, & DeCarlo, 1995; Sheinkopf & Siegel, 1998). The UCLA research was especially controversial because it demonstrated that 40% to 50% of the children recovered. Before this time, it was common wisdom that children with autism could learn and mature, but little credence was given to the goal of recovery or achievement of typical psychosocial functioning.

Gradually, some parents became aware that the goal of recovery might be within reach for their own children. Information about the option of early intensive behavioral intervention

(EIBI) involving discrete-trials training and a clear instructional sequence was provided through presentations at conferences at which there were many parents seeking the best possible services for their children. Assertive advocacy by parents for these types of services gained momentum and has become commonplace (e.g., Parents for Early Intervention, 1995). Parents have found, however, that getting these services is no easy matter.

Research from UCLA and a number of other sources has been based on especially intensive services, involving clinic-, home-, and school-based teaching and training, and entailing considerably more hours of service than has been generally provided to children in early intervention (Green, 1996). Parents have frequently found themselves engaged in extended due process hearings in order to obtain these services, because local educational agencies and early intervention providers have resisted investment in more expensive services. It would be a mistake, though, to attribute school resistance to intensive intervention to cost alone. There is also a lack of knowledge in many schools about the benefits of discrete-trial and applied behavioral services for these children, and a lack of knowledge about the essentials of behavior analysis. As one parent noted in an E-mail message:

[Regarding] our 3 year old son. . . . [We] have spoken to the child study person and have tentatively set up a meeting. . . for initiation of the IEP [Individual Educational Plan]. We haven't had much luck communicating with the child study person, she seems totally and permanently confused. She has offered us one program to look at, a . . . program which is a very sad excuse for [applied behavior analysis], doesn't even come close and can't even be compared to any even shabbily run [applied behavior-analytic] program. We have told her that we want to implement a home program, which she knows nothing about, and asks no questions of us to enlighten herself.

My husband called the school to speak to the superintendent, and he knows nothing about our upcoming meeting or our son or our request. He then calls the child study person, and calls us back and sets up a meeting tomorrow to discuss the costs of our proposed home program. Now

keep in mind that there is no IEP. He knows nothing about this three year old child, and basically nothing about our proposed program, but he wants to discuss the cost of such a program. . . . I read about the law and the spirit of IDEA [Individuals with Disabilities Education Act], and then I see this kind of stuff in action, and I feel really concerned about the future of our children's education.

I am so unbelievably surprised by the lack of education, and lack of professionalism in almost everyone I have met since the autism was diagnosed. . . . It's not a sin to be uninformed, it's a sin to stay uninformed.

Before considering some of the reasons why educators often are unaware of, or may reject, the evidence for EIBI, it is helpful to put the issues in context by looking at what it is that parents want and the services that the educational sector provides.

### **WHAT PARENTS WANT, AND WHAT SCHOOLS PROVIDE**

#### *Growing Demand with Growing Numbers of Children*

The impetus to advocacy for services for young children with autism has been fed by what appears to be a substantial increase in the numbers of children diagnosed with autism (including PDD and Asperger syndrome; Talan, 1999). Statistics from the federal Department of Education (1999) show that enrollments of children aged 0 to 21 years with autism and related conditions in U.S. schools have increased from 5,000 students in 1991–1992 to 45,000 in 1996–1997. A recent report from the California Department of Developmental Services (1999) identified an increase in reported people with autism of 210% between 1987 and 1998, with about 12% to 13% of people with autism reported in 1998 consisting of children aged 0 to 4 years.

The factors underlying these increases are not well understood (Gillberg, Steffenburg, & Schaumann, 1991; Kolata, 1999; Taylor et al., 1999). Possible factors include referral of increased numbers of children with autism but without mental retardation to practitioners for differential diagnostic ser-

vices (Bloom, Sears, Allard, Weiskopf, & Williams, 1999), diagnosis of children with milder forms of autism spectrum disorders in lieu of mild mental retardation (J. A. Mulick, personal communication, 1999) or some forms of specific learning disability (e.g., nonverbal), increased usage of the classification of autism in diagnosis of disorders by community clinicians who have become more aware of the nature of this condition, changes in diagnostic criteria with publication of successive nomenclatures, and bioenvironmental influences (e.g., disease, iatrogenic, teratogenic, or mutagenic) that are affecting an increase in rates. Regardless of which of these factors are affecting the rate of autism spectrum disorders, there has been a marked increase in the numbers of identified and reported children. This has brought a corresponding broadening demand for early intervention, preschool, and school services. These increased numbers translate to an increased constituency engaged in advocacy for EIBI at many levels of the human services sector, including county service systems and individual school districts.

#### *Parents Seek High-Quality Services*

The consensus of opinions obtained from parent advocates in conversations, in Internet messages, or on organization Internet sites is that their children must be able to get services, regardless of how they are obtained or paid for, that have the prospect of real benefits. For preschoolers this means that they get services rapidly, that the services are local and accessible, that the services are there for as long as they require them, that the people who provide and supervise the services are competent, that providers are honest, forthright, specific, and clear in their communications, that providers explain why they are using the methods that they use, and that parents are involved intimately in all of the important educational and treatment decisions involving their children (e.g.,

Hartnett, 1999; Maurice, 1993; Maurice et al., 1996). These types of parental concerns are not limited to utilization of behavior-analytic services or development of services for children with autism, but they are particularly relevant in the context of behavior-analytic services for children with autism and related conditions.

Not all parents articulate these goals in their entirety, but these goals are characteristic of what many parents do articulate as reasonable and desirable early intervention and educational practices, as well as practices that many professionals would consider to be indicators of high-quality early intervention services (e.g., Ramey & Ramey, 1992). The following excerpts from a letter from parents to a school district, placed by those parents on the Internet, exemplify rising parent expectations:

We are not here to ask any more for our child. He is fortunate to have parents with the time and financial resources to get him the help he needs without the cooperation of or even against the opposition of the school administration. But we are afraid for the many other children with [autism spectrum disorders] who are clearly not receiving the services they need and deserve. It is very sad that the school has made a conscious decision to ignore the results of over 30 years of research on developmental disorders. . . . We simply do not know where to turn when, for example, we send an administrator research papers on recovery from autism and are told that this action is "pushy, in-your-face," and that statistically valid results are "just your opinion."

The program we have crafted for [our child] does not rely on "philosophy." It certainly does not depend on trust—we were asked, in fact, not to trust our consultants, or the therapists, or even ourselves, but to judge only by results, only by [his] measurable progress. It is not new, or experimental; children have been recovering from autism since the 1960's. . . . But there is one essential program component which we cannot provide, even with legal intervention, and that is a school with an open mind. For that reason we are soon moving to another district that uses research and cooperation, not litigation, to craft effective programs. (Saffran & Saffran, 1997)

All too often, parents have found that there are long waiting lists for services (National Autism Society, 1999), that they must undergo extended due

process to get services, that when they get funding there are no adequate local services. They have also discovered that arbitrary time limits are imposed by regulations, policies, or annual planning practices and these decisions are not based on child- or family-centered criteria, that training of personnel in discrete-trial or other behavioral methods has been little more than a gesture, that providers are unwilling or unable to describe why services are provided in a particular way, and that parents are excluded from a variety of important decisions, including the timing and nature of teaching and integration arrangements (e.g., Peper Martin Law Firm, 1999).

### *Survey of Parent Concerns*

Surveys completed by 300 to 400 parents of children with autism from four regions encompassing New York State were obtained by Hartnett (1999). The purpose of the survey was to identify common issues encountered by parents. Representative respondents were quoted as saying, "When my child transitioned from his preschool program to our local public school, his education and rehabilitation ended . . . and he immediately regressed. . . . No one in the district had experience, training, or understanding of my child's needs" (p. 4), and "Empirically validated research-based instruction should at least be an option for every child with autism in this state" (p. 5); yet another parent said, "Services vary greatly dependent upon where the child lives. There are major differences from one district to another" (p. 5). With special pertinence for behavior analysts, one parent summarized the situation encountered in attempting to obtain high-quality behavior-analytic services as follows: "I believe that [behavior-analytic] programs are highly effective for most autistic children. . . . Current school programs do not have adequate staff ratio for a quality program . . . lack of resources . . . space problems . . . increased and more in-

tensive and ongoing training is required, as well as much, much, more supervision" (p. 6). Parents also called for the schools to be more responsive to expert advice, with one saying, "All we are trying to do is get the same type of services for our son as children with autism are receiving in neighboring counties. Even with consistent recommendations from a developmental pediatrician, a clinical psychologist, several evaluators, my son's special education teacher, OT [occupational therapist], PT [physical therapist], and speech pathologist . . . the school district refused to consider their recommendations or ours" (p. 6). These quotations were selected by Hartnett as representative of common and typical statements by parents about what has occurred when they sought individualized and responsive school services for their children with autism.

#### *Survey of Autism Educator Concerns*

The problems associated with providing applied behavior-analytic services that have been identified by educators parallel and complement those identified by parents. Pertinent information on implementation issues in preschool and special education for children with autism was collected from regular and special educators in New York by Mingin (1999). Educators reported pervasive needs for additional training regarding (a) autism spectrum disorders, (b) managing aggression, (c) appropriate assessment methods, (d) developing services based on behavior analysis, Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), and floor-play therapy procedures, (e) including autistic children in the general school classroom and activities, (f) integrating social goals within the classroom, and (g) postsecondary school transition for adolescents with autism spectrum disorders. Mingin found, moreover, that districts have "learned to listen" to parental requests more carefully, because

parents often arrive at the school not with greater knowledge about their children but about autism and educational or related service methods. Teachers stressed needs for staff training that is ongoing, supervised, and hands-on, and for specialists with skills in autism and behavior analysis, rather than generalist special educators, to assist with many aspects of educational service organization and delivery.

Shortages of teachers with training and background in autism and of appropriately experienced related services professionals were common as well (Mingin, 1999). Some school districts had reconstituted or expanded educational teams to achieve both greater inclusion and improved instructional design for these students, but clearly, shortages of trained resource personnel with the needed experience in autism and behavior analysis impaired the capacity of many other districts to introduce similar organizational and team changes (Mingin, 1999). A key aspect of a specialist team suggested by both Hartnett (1999) and Mingin was required participation by educational or related services personnel with expertise in behavior analysis and autism.

But why do parents find that they have to fight for the types of services that have demonstrated benefit, and how it is that early intervention service providers are generally not adequately prepared to provide these services? Why is it that educational agencies or educators are found to be personally and professionally opposed to providing any type of services based on behavior analysis?

#### *Present Educational Practice and Parent-School Conflict*

Following a first diagnosis of autism, parents who seek services for their young child are confronted by a bewildering array of intervention approaches (Mack & Webster, 1980; Maurice, 1993). As listed by one parent in an E-mail message, these include behavior analysis (e.g., "Lovaas ther-

apy," discrete-trial training, behavioral therapy), vitamin therapy, dietary interventions, anti-yeast therapy, auditory integration therapy, sensory integration therapy, music therapy, holding therapy, osteopathy/craniosacral therapy, Son-Rise program, swimming with dolphins, speech therapy, special education, and psychoanalysis (e.g., Smith, 1996). There are two key features of this list of interventions. First, the only one with outcome data that demonstrate that children have gained extensively and regularly, either in terms of recovery or consistent improvements in development compared to peers, is behavior analysis (Green, 1996, 1999; New York State Department of Health, 1999; Smith, 1996). Second, there simply are no outcome data on the effects of inclusive education, the present major thrust of special education service reform, on the development of children with autism (e.g., Simpson, 1995; also, more generally, see Kauffman & Hallahan, 1995).

Although there are limited data on the rates at which a number of the treatments in the list above are used, it is common for parents to obtain a combination of interventions that is highly eclectic, and may entail specific procedures that are inconsistent or conflicting in their methods. Parents are rarely given information regarding the foundations or evidence of various interventions, and have limited access to specific information regarding the effectiveness of behavior analysis (Jacobson, 1999). At a 1997 conference in Cortland, New York, sponsored by the New York State Association for Behavior Analysis, where the evidence for various services was discussed, some parents objected to presenters who stressed that there are data showing clear benefits from behavior analysis, but no outcome data showing these benefits for other education or treatment options.

Many parents who have chosen these other options, in many instances long ago because their children are

now in secondary school or young adults, have done so on the basis of professionals, educators, and other parents encouraging them to use particular interventions that professionals or educators habitually provided and that have been portrayed to hold promise of benefit. There is no outcome or comparative research indicating broad or even, for many interventions, narrow benefits from these therapies or educational strategies. Parental decisions have also reflected the best information available at the time they made the decisions or began a course of treatment.

Thus, the recommendations by professionals or other parents that led to these options were based on faith, their professional training, or descriptive reports in the literature that reported outcomes in subjective terms and did not compare results to those for untreated peers. The fact that specific or comprehensive outcomes of alternative therapy options have not been experimentally and scientifically demonstrated is not tantamount to stating that the other options listed are harmful, totally ineffective, or of small benefit. However, if the options are inherently incompatible with applied behavior analysis, their use could militate against achieving benefits from behavior-analytic and related procedures, and it is possible that adoption of eclectic or alternative approaches by parents as predominant strategies could forestall timely access and implementation of effective procedures (Jacobson, Mulick, & Apollo, 1998). It is possible that the effects of many poorly researched intervention procedures are, in fact, totally ineffective or harmful (Green, 1999).

In some cases, parents who select particular nonbehavioral interventions, clinicians and educators who refer them or provide such services, and school districts that implement particular forms of nonbehavioral intervention may do so based on their compatibility with their own values, beliefs, and philosophy toward life, health, and education, rather than because of rejection of applied behavior analysis

(American Association of Retired Persons, 1999; Astin, 1998). In other cases, however, parents may be discouraged from seeking further information about, or obtaining, behavior-analytic services (e.g., Autism National Committee, 1999a, 1999b), based on philosophical rejection of behavior analysis by advocates, educators, or administrators.

In general, certification and licensure of professionals, including educators, constitute a social contract between practitioners and society; in exchange for the social and economic privilege of offering exclusive or particular services, practitioners essentially contract to provide those services in an effective and socially conscious manner. In several of the health- or education-related professions, including medicine, psychology, and speech pathology, practitioners are required by ethical standards associated with licensure to practice within their competence, to place special emphasis and priority on practices that are validated by objective, controlled, and outcomes-referenced research, and to change their practices as the state of knowledge evolves in relation to that research. Yet, Maurice's *Let Me Hear Your Voice* (1993), a book that informs parents in detail about EIBI, describes a journey through false leads, misrepresentations, victimization, and demonstrated lack of contemporary knowledge involving a succession of educators, physicians, psychologists, and other professionals, as well as entrepreneurs. Consider what might be the ethical and professional position that underlies one professional Maurice encountered:

I asked her what the [agency] thought of behavior modification.

"Behavior modification is totally against the child. It turns the child into a robot."

"Have you read any of the recent literature about the recovery of some children through intensive behavior modification?"

"I don't read the literature. I know from my own experience that behavior modification is totally against the child." (Maurice, 1993, p. 276).

The key phrase here, of course, is "I don't read the literature." How could a professional learn about research or clinical practice findings of any consequence if he or she relied only on word of mouth as a source? Yet, this may be a prevailing source of information for many professionals who work in early intervention and who may not have an obligation to participate in continuing professional education.

Maurice (1993) also vividly portrays her own reaction to being repeatedly given conflicting recommendations and vague promises, a reaction that may be all too common as the trust of parents is abused by well-meaning but ill-informed workers:

Today I have learned to recognize the dangerous words: words like "rebonding" instead of "teaching"; "emotionally disturbed" instead of "ill"; "psychotic mother" instead of "heartbroken mother"; "cure" instead of "recovery." I have learned to beware of anyone who sells a miracle, then explains away the failure to get one by implying that the parent does not have the proper mind set, the right attitude for healing his child. (Maurice, 1993, p. 285)

Although Maurice's search involved contact with professionals with varied backgrounds, in New York and many other states early intervention and preschool services fall within the purview of health or educational sectors. Parents of children with disabilities have become increasingly concerned that public resources be widely used and dedicated to services that make a difference and effectively achieve their stated goals (Grossen, 1997). Many citizens believe that the quality and effectiveness of public education is one of the most important social and political issues in the United States today (Crandall, Jacobson, & Sloane, 1997; Skinner, 1984). Why then, in the case of educational and health-related services for children with autism, do we find that most of the services that providers are prepared to offer are based on personal opinion, accumulated subjective consensus, or sometimes ideological positions instead of practices

with demonstrated outcomes? Why don't these educational and clinical services have more to do with the question of whether children are learning?

These questions are addressed by an article initially published on the Internet by Grossen (1997) entitled "What does it mean to be a research-based profession?" Grossen suggests that the primary foundation for educational practice, including early intervention practice, is largely a matter of shared folklore among educators and a hearty disavowal of research findings. She describes three levels of research, each of which is logically more compelling, ranging from descriptive or how-to studies, to comparative studies of educational practices, to demonstrations of excellence that involve spreading practices. She recounts how the techniques that are most widely used are based on research and demonstrations that are descriptive in form. The basis for their use is almost entirely a matter of philosophy and social preference (see also Kauffman, 1996).

Grossen also discusses Project Follow-Through, the largest comparative and demonstration project of early intervention ever conducted, a collaborative national study involving 70,000 children at risk or with various disabling conditions typical of children entering Head Start programs (Watkins, 1997). The findings from this study were that direct instruction, a group of methods related to behavior analysis, and another behavioral approach achieved statistically and pragmatically superior outcomes for these children, when contrasted with more popular educational models. Faced with findings from the study that were "philosophically incorrect," Grossen notes that a 1981 report from the National Institute of Education stated that the findings should be disregarded because they involved (a) scientific research approaches and (b) accountability in education (i.e., whether and what children learn when taught in certain ways) and were irrelevant for teachers.

Grossen advocates that educational settings that do achieve learning objectives should be identified, and that these educational settings should be encouraged to become the primary contributors to a shared knowledge base of effective practices. This is exactly what some professionals are attempting to achieve in developing competent delivery of discrete-trial and other behavior analysis services for children with autism.

Thus, there are several converging contingencies in contemporary EIBI and special education that fuel dissension and conflict among parents and schools. Briefly summarized from above, or notable in the literature on school reform (e.g., Skrtic & Sailor, 1996) these include (a) emphasis on school restructuring and inclusive education that also deemphasizes or diminishes the role and significance of instructional methodology or efficacy; (b) a shortage of educators in local schools who are sufficiently trained and experienced in both autism and behavior analysis; (c) heightened demand by families for EIBI and behavior-analytic school services for children with autism; (d) a research literature on EIBI and applied behavior analysis that is not consistently used by educators; and (e) continuing demands on public education administration to control rising educational costs, especially special education costs (e.g., Illinois Association of School Boards, 1999) and associated increases in local school tax levies.

### **FACTORS THAT INFLUENCE CURRENT EDUCATIONAL PRACTICE IN AUTISM OR PDD**

Aside from such fundamental issues as financing that affect the capacity of educational systems to address student needs, there are additional concerns, some political and philosophical and others relating to the state of knowledge in education, that affect the content, intensity, and location of early intervention, preschool, and educational



services offered to children with autism or PDD.

### *Political and Philosophical Concerns*

As already noted, some contemporary and influential formulations of special education and the role of special educators stress particular social-political views (e.g., Biklen & Cardinal, 1997; Skrtic & Sailor, 1996). Rather than stressing, as practitioners trained in a therapeutic tradition might, effectiveness of educational services, these formulations focus upon the social context of educational services, with emphasis on physical presence within typical educational classes (e.g., full inclusion). This position is consistent with the democratic principles of voice, participation, and inclusion (Skrtic & Sailor, 1996). From this standpoint, where a person is educated is more important than whether he or she is educated (e.g., learns and develops new skills).

Such views disavow conventional research foundations of educational decision making (Biklen & Cardinal, 1997; Kauffman, 1996) and focus on the physical movement of students from one place to another (Kauffman & Hallahan, 1995). As recently as 1996, one review of inclusion and educational practice concluded that

There is no compelling evidence that placement rather than instruction is the critical factor in academic or social success. Further, studies have indicated that typical practice in general education is substantially different from practice in the model programs that showed greatest success for students with disabilities. The interventions that were effective in improving academic outcomes for students with disabilities required a considerable investment of resources, including time and effort, as well as extensive support for teachers. . . . The research does not support full-time inclusion for all students with disabilities. On the contrary, it appears that there is a clear need for special education. (Hocutt, 1996, p. 77)

Similar conclusions have been reached by providers of autism educational services:

Inclusion should never replace a full continuum of service delivery, with different students

with autism falling across the full spectrum. Full inclusion should be offered to all persons with autism who are capable of success in fully integrated settings. Partial inclusion is expected to be appropriate for other clients with autism. And special classes and schools should be retained as an option for those students with autism for whom these settings are the most meaningful and appropriate. (TEACCH, 1999b, p. 2)

### *Regulatory Requirements and Evaluation Standards in Education*

Some changes in regulations underlying special education practices seem to be consistent with an approach based on effectiveness. Although states vary in their standards regarding requisite educational benefit from special education and an individual educational plan, some states, including Iowa, Kansas, Massachusetts, Michigan, Missouri, New Jersey, and Tennessee, have enacted laws or established regulations that require substantial or maximal benefits, or related practices that may promise such benefits (White, 1999). However, these requirements have not been fully tested in some states, or have been vitiated in their interpretation in hearing decisions (Chackes, 1999; White, 1999). Absent such requirements, local educational agencies in most states can satisfy standards for educational benefit through the demonstration of small, even pragmatically and socially insignificant, improvements in a child's performance as the result of participation in special education.

A recent extensive series of messages on the Psych-DD Internet listserv entailed discussion regarding whether students are entitled under IDEA (Individuals with Disabilities Education Act, as amended) to inclusive education. The discussion was initiated by several list members at different colleges or universities who had been informed of this "right" in undergraduate education courses. However, guidance materials regarding rights and procedures under IDEA, developed under contract from the U.S. Department of Education, indicate otherwise, as

shown in the excerpts below regarding the two principal rights related to inclusion: (a) least restrictive environment (LRE), and (b) free and appropriate public education (FAPE).

A child's LRE is the environment where the child can receive an appropriate education designed to meet his or her special educational needs, while still being educated with nondisabled peers to the maximum extent appropriate. Depending on the child's individual needs, the LRE could be, for example, . . . a special education class within the child's neighborhood school; or even a separate school specializing in a certain type of disability. (National Information Center for Children and Youth with Disabilities [NICHY], 1999b)

Upon reading the definition [of free appropriate public education], [it] becomes clear [that] the law requires: . . . that the services are provided in keeping with what has been decided in the IEP meeting of the student and written down in that student's individualized education program (IEP). . . . What is not immediately clear about FAPE, but which is true nonetheless, is that for each student with a disability FAPE is different . . . what is "appropriate" for one student will not be appropriate for another. A great deal pivots on the requirement of "appropriate."

It is useful to briefly consider how an appropriate education is determined. . . . A process of discovery is necessary to define what is appropriate for each student. The process begins with an individualized evaluation, where the student's areas of strength and weakness are identified. . . . Under IDEA 97, as never before, this evaluation must also provide information relative to the student's participation in the general curriculum [Section 614(b)(2)]. Next, the IEP Team uses the evaluation data to discuss and develop an IEP. (NICHY, 1999a)

Despite such legal bases for effective individualized programs, inclusive education is sometimes typified as largely incompatible with intensive intervention, such as behavioral intervention, or as being difficult to implement in a fully inclusive context (Hocutt, 1996). Moreover, the rate of inclusion of students with disabilities is used as a quality benchmark by the Department of Education. Although reviews (e.g., Hocutt, 1996) and legislative content (NICHY, 1999a, 1999b) reinforce the perspective that educational placement and instructional decisions should be made on an individual basis, instruction to teachers in training and administrative reviews may reinforce more

uniform decisions at the school level, which stress inclusion and possibly deemphasize instructional intensity, thus diminishing access to intensive instructional services.

Although segments of the special education community have dismissed research as a touchstone for service design, evaluation research standards have been established for educational services, based on consensus among 16 professional associations (Ducharme, Licklider, Matthes, & Vannatta, 1999; ERIC Clearinghouse, 1995), and stress the following characteristics:

Sound evaluations of educational programs . . . should have four basic attributes: Utility: . . . ensure that an evaluation will serve the information needs of intended users. . . . Feasibility: . . . ensure that an evaluation will be realistic, prudent, diplomatic, and frugal. . . . Propriety: . . . ensure that an evaluation will be conducted legally, ethically, and with due regard for the welfare of those involved in the evaluation, as well as those affected by its results. . . . Accuracy: . . . ensure that an evaluation will reveal and convey technically adequate information about the features that determine worth of merit of the program being evaluated.

. . . Procedures should be chosen or developed and then implemented [to] . . . assure that the interpretation arrived at is valid for the intended use . . . procedures should be chosen or developed and then implemented [to] . . . assure that the information obtained is sufficiently reliable for the intended use . . . information collected, processed, and reported in an evaluation should be systematically reviewed and any errors found should be corrected . . . conclusions reached in an evaluation should be explicitly justified, so that stakeholders can assess them . . . [and] reporting procedures should guard against distortion caused by personal feelings and biases of any party . . . [and assure] that reports fairly reflect the evaluation findings. (ERIC Clearinghouse, 1995)

Review of research on a wide range of alternative treatments for autism, and related educational or preschool and school practices, including those that may be presented in pre-service or continuing education activities for educators, has indicated that many of the studies of treatments and practices do not have procedural or reporting characteristics that meet these criteria (U.S. Department of Health and Human Services, 1999; Grossen, 1997; Kauffman

& Hallahan, 1995; Smith, 1996; Viadero, 1999a, 1999b). Thus, despite government-mandated evaluation of programs and professionally determined standards for such evaluation, it is still left up to parents to promote effective services.

### **PARENTAL STRATEGIES AND RESOURCES TO PROMOTE BEHAVIOR-ANALYTIC SERVICES IN SCHOOLS**

#### *Due Process and Litigation at the Individual Level*

Since the inception of federal legislation guaranteeing a free and appropriate education for children with disabilities in the least restrictive setting (e.g., Education for All Handicapped Children Act, P.L. 94-142, enacted in 1975, and subsequently amended as the IDEA amendments of 1997, P.L. 105-17), parents who disagree with elements of their child's individual education plan have had recourse to due process in appealing these elements. Due process includes alternatives such as extended negotiation between parents and the schools, nonjudicial appeals and impartial hearings (with hearing officers), and judicial hearings (with judges) to resolve disputes. Procedural requirements with respect to (a) development and delivery of individual educational services and provision of (b) an appropriate education in (c) a least restrictive setting (which may be treated as related or separate issues depending upon the child's educational and related service needs or the services and placement planned for the child) have formed the basis on which disputes have typically arisen. Determinations may be rendered in favor of the schools or the child, and trends toward decisions that favor the child do not appear to be pronounced (see Appendix A). Appendix A shows the primary federal legislation relevant to special education, representative cases in which children or schools prevailed, and the character of decisions regarding autism or PDD-related be-

havior-analytic services in schools. One source (Peper Martin Law Firm, 1999) suggests that the numbers of such cases brought by parents on behalf of children with autism or PDD have been growing, from one to several cases each year during the early 1990s, to 10 in 1995, and 30 in 1996.

In cases in which parents have prevailed in due process or litigation, districts commonly "had proposed 'one size fits all' early childhood programs and placements, offered programs of 20 hours or less, resisted using [behavior-analytic] methods, or had staff who are not sufficiently trained in autism, PDD or behavioral modification techniques" (Peper Martin Law Firm, 1999). In cases in which districts have prevailed, "staff were trained in applied behavioral analysis and willing to adopt these strategies, some one-to-one instruction was provided, at least 20 hours per week of programming was provided, there was meaningful participation by parents, staff were willing to consider parent recommendations regarding behavior analysis, and outside consultants or experts were hired" (Peper Martin Law Firm, 1999). Appendix B shows disputes and the substance of decisions related to parental reimbursements for behavior-analytic costs during the period 1988 through 1998. The disputes listed in Appendix B also include cases in which school districts successfully avoided liability for behavior-analytic services.

#### *Internet Advocacy for Group Action and Social Change*

A wide range of organizations and associations advocate improvement in the treatment and education of children and adults with autism or PDD, with a strong presence on the Internet. The groups related to research on autism or PDD include Cure Autism Now (CAN) and Defeat Autism Now (DAN), which stress biomedical, alternative medicine, or selected behavioral science approaches to autism; the National Association for Autism Research

(NAAR), which promotes biomedical research on autism, including genetic research; and the Association for Science in Autism Treatment (ASAT), which promotes scientifically and empirically validated treatments based on behavioral and medical science.

Other organizations have more extensive social action agendas. One is the Autism National Committee (AUTCOM), an association that opposes behavior-analytic treatments for autism, and supports "developmental approaches" and movement therapies which are not well explicated, as well as facilitated communication, "dedicated to 'Social Justice for All Citizens with Autism' through a shared vision and a commitment to positive approaches" ([autcom.org](http://autcom.org)). Another is CIBRA (Children Injured by Restraint or Abuse), "a national/international support network for parents whose children (including adult children) have been traumatized, injured or killed by abusive behavior modification . . . and restraint" ([users.1st.net/cibra](http://users.1st.net/cibra), August 28, 1999).

European organizations that focus on autism and autism services, including various depictions of behavior analysis, are also present on the Internet, with sites in France, Great Britain, Ireland, Northern Ireland, Luxembourg, Sweden, and Spain. There is also a European association, Autism-Europe, whose main objective is to "advance the rights of people with autism and their families and help improve their lives. . . . Autism-Europe coordinates the efforts of 71 national and regional associations of parents of children with autism in 29 European countries, including 14 Member States of the European Union" ([autismeurope.arc.be](http://autismeurope.arc.be)). There is also the World Autism Organization ([worldautism.org](http://worldautism.org)), founded in 1998, a rights organization relating to WHO (the World Health Organization) and UNESCO (the United Nations Educational, Scientific, and Cultural Organization).

The historical position of groups that advocate in a broad manner for chil-

dren and adults with autism and their families has been to encourage access to a broad range of services. Possibly due to the perspective that research has not demonstrated substantial rehabilitative potential, and in order to embrace potential members who have made diverse treatment selections, the common advocacy posture on the Internet is to advocate access to both a wide range of long-term services and a wide range of therapies. This perspective is exemplified by the options policy of the Autism Society of America (1999):

The Board of the Autism Society of America believes that each person with autism is a unique individual. Each family and individual with autism should have the right to learn about and then select, the options that they feel are most appropriate for the individual with autism. To the maximum extent possible, we believe that the decisions should be made by both the parents and the individual with autism. . . .

We firmly believe that no single type of program or service will fill the needs of every individual with autism and that each person should have access to support services. Selection of a program, service or method of treatment should be on the basis of a full assessment of each person's abilities, needs and interests. (Adopted by the ASA Board of Directors 4/1/95; at [www.autism-society.org/society/options.html](http://www.autism-society.org/society/options.html)).

Other broad-based national societies also support parental use of, and provide Internet links to, a range of empirically studied, conventional, unconventional, and questionable therapies. For example, the World Wide Web site for the Society for the Autistically Handicapped in the United Kingdom, which lists over a dozen treatment options with varying scientific validation, notes that

Every treatment for autism has its detractors and none has proven to benefit every case. Thus, the task of judging the effectiveness of potential treatments will ultimately fall on you—to a larger extent than you will feel qualified to make. If the professional to whom you take your child strongly recommends some program or treatment, know that there are others who will recommend some other just as strongly. Note that many programs are made up from parts of several methods. . . . There is no standard, universally accepted treatment of autism; in fact, every single method has its detractors. (Society for the

Autistically Handicapped, 1999, <http://www.autismuk.com>)

Such perspectives are mirrored, in large part, by summaries that are presented on the Internet by some professional services sources as well, although with a somewhat more specific focus. For example,

Presently, there is no documented cure for autism. Autism can be treated, however, and some people with the disorder are eventually able to live reasonably normal lives. In isolated cases, medically based treatments such as special diets or medication have been effective in reducing the symptoms of autism. For the majority of people with autism, the most effective treatment is an individualized educational program designed to address the communication and social deficits associated with the disorder. (TEACCH, 1999b, at [autism-info.com/teacch.html](http://autism-info.com/teacch.html))

Links to conventional and unconventional therapies maintained by Internet sites of advocacy organizations lead to other sites that may provide national listings of local therapists, private or organizational practitioners of specific therapies such as "Greenspan" or floor-time play therapy [i.e., for whom a list is presented in conjunction with the Unicorn Children's Foundation ([saveachild.com/legend.htm](http://saveachild.com/legend.htm)), or physicians who administer particular drug treatments ([autism.com/ari/danlist.html](http://autism.com/ari/danlist.html))]. Thus, the Internet has emerged as a source of direct referral for services with validation of effects that vary indiscriminately from non-existent to substantive. However, more discriminate recommendation of services is possible if standards that require scientific evidence of benefit are adopted—stipulating neither that universal and uniform benefit must be demonstrated nor that all detractors of all methods must be credited (e.g., Green, 1996; Smith, 1996). In applying these standards, a more contemporary cadre of advocacy groups has emerged, which emphasize scientifically validated treatment procedures for autism, including applied behavior analysis.

The largest association presently advocating behavior-analytic treatments of autism is Families for Early (or Effective) Autism Treatment (FEAT). As

of August 1999, at its Internet site ([feat.org](http://feat.org)), FEAT reported 26 chapters or affiliates under this acronym, and about an equal number of kindred organizations with similar purposes, in Canada, Mexico, and 28 U.S. states, established since 1993. The primary purposes of FEAT are

To provide treatment resources for families with children diagnosed with autism and related disorders between the ages of 18 months and 18 years.

To provide support, encouragement, and guidance to parents seeking treatment for their young autistic children and to create an opportunity for parents to benefit from contact with other parents with similar concerns.

To evaluate and compare effectiveness of current treatment approaches and make treatment information available to parents.

To maintain and make available a resource library of materials to be used in treatment programs for autistic children and regarding autism and related disorders.

To organize a long-term, cost-effective program to help parents effectively teach developmental skills. ([feat.org/FEATorg/bylaws.htm](http://feat.org/FEATorg/bylaws.htm))

Various chapters of FEAT present forthright depiction of treatment issues in autism, and represent an important first contact Internet resource for introducing information about behavior-analytic treatments to families:

Autistic children are taught how to overcome their learning limitations with intensive, non-aversive, one-on-one training programs—programs being replicated by educational institutions and in homes nationwide. (FEAT of Houston, 1999, at [neosoft.com/FEAT\\_Houston/](http://neosoft.com/FEAT_Houston/))

Effective, scientifically backed treatment for autism exists (the "Lovaas" Method—a form of Applied Behavior Analysis). Lovaas behavioral treatment for autism is medically necessary and prescribed by physicians because it is the only treatment available that significantly improves this biological disorder. Lovaas behavioral treatment for autism is the most thoroughly documented treatment of children with autism. . . . (63 [British Columbia] psychiatrists have endorsed the Lovaas autism treatment method as medically necessary intervention that should be funded under Medicare; signatures are on file). (FEAT of British Columbia, 1999, at [fox.nstn.ca/~zacktam/FEATbc/index.htm](http://fox.nstn.ca/~zacktam/FEATbc/index.htm))

Although FEAT chapters probably represent the primary parent-developed and -accessed sources of information about behavior-analytic treatment of autism on the Internet (see, e.g., the

FEAT of Memphis site at [geocities.com/Heartland/Plains/1648/](http://geocities.com/Heartland/Plains/1648/)), it does not represent the only source. Numerous other organizations are listed at the [feat.org](http://feat.org) Internet site. Kindred groups include Parents for the Early Intervention of Autism in Children (PEACH, with about 850 members) in the United Kingdom, "a parent-run support group advocating early, intensive behavioural intervention for children with special needs" ([peach.uk.com](http://peach.uk.com)), the New Jersey Center for Outreach and Services for the Autism Community (COSAC; [members.aol.com/njautism/](http://members.aol.com/njautism/)), and New York Families for Autistic Children (NYFAC; [albany.edu/psy/autism/nyfac.html](http://albany.edu/psy/autism/nyfac.html)).

In the United Kingdom, the National Autism Society local affiliates have often become providers of services. Today, "most affiliated societies tend to concentrate their resources on either direct provision through schools and/or adult services, or on family support and the promotion of awareness among central and local government and the general public. More recently some of the larger direct-service providing local societies have started to develop their work into a broader base of activity" (National Autism Society, 1999, [oneworld.org/autism\\_uk/nas/nasworks.html](http://oneworld.org/autism_uk/nas/nasworks.html)). Similarly, it is evident that, due to local unavailability of EIBI programs or practitioners, FEAT chapters have also begun providing services.

In addition to organizational or society sites on the Internet, listservs have become a major source of more detailed and sometimes conflicting information on the nature and treatment of autism. It is evident that many parents are aggressively seeking information particular to applied behavior analysis as a principal treatment for autism through listservs. One E-mail list, the ME-list service, which focuses on behavior analysis and autism, is a case in point. "As of August 28th [1999], there were 3,050 E-mail addresses subscribed to the [ME-list] . . . A rough estimate would be that the list actually reaches between 2,000 and 2,200 peo-

ple each day. The majority are parents, but there are of course a significant number of professionals on the list as well" (Allen, 1999). The Behav-An Internet listserv has between 750 and 891 members depending upon method of subscription (Plaud, 1999) and the Psych-DD Internet listserv has remained stable during 1999 at 510 to 540 members (Kolstoe, 1999). Subscribers to the latter lists are primarily professionals and workers or managers in the fields of behavior analysis or developmental disabilities, but do include parents and advocates, and content of these lists is not largely confined to autism issues.

### **CONVERGING INTERESTS OF PARENTS AND PROFESSIONALS**

The types of quality-control problems that exist in early intensive intervention have been long-term concerns for professionals in behavior analysis (Johnston & Sherman, 1993; Shook, 1993; Wood, 1975), including those who focus on developing pragmatic solutions to how we serve children (Maurice et al., 1996; Shook, Hartsfield, & Hemingway, 1995). Parental assertion of the need for ready access to high-quality intensive early intervention has revitalized interest among many professionals in behaviorally based services. As one parent professional has noted, "Despite the best intentions of special educators to provide a meaningful learning environment . . . the impaired learning style of the young autistic child and the lack of opportunity for high-level teacher training have dampened or completely thwarted effective early intervention in most school environments" (Huff, 1996, p. 251). Moreover, children with autism represent a small (but growing) segment of all children who take part in early intervention, with the majority classified as at risk or with conditions such as mental retardation or pronounced motor disabilities. Quality-control problems represent profound threats to the

effectiveness of intensive early intervention services and policy, and pose the very real possibility that, unless action is taken to correct them, intensive early intervention policy will become a debacle and eventually looked back upon as a travesty of human and public service.

The solutions that professionals in behavior analysis have identified thus far to address quality control involve standard setting (Autism Special Interest Group, 1998) and professionalization through certification (e.g., Starin, Hemingway, & Hartsfield, 1993). Certification addresses the core issues from which service quality problems encountered by children with autism stem: lack of adequate preparation of personnel in behavioral methods and the lack of means to assure that people and organizations, including schools, that purport to provide intensive intervention actually possess the competence to do so (Shook et al., 1995). If personnel were more comprehensively trained, for example, they would also be more knowledgeable about the approaches that have demonstrated the most benefits for children with autism and on what basis.

Although it is common knowledge among behavior analysts, interested public constituencies who may influence public policy development do not necessarily know that, although most people who are skilled and highly experienced in behavior analysis are educators or psychologists, most educators and psychologists are not highly skilled in behavior analysis. Some proposed laws or regulations have stipulated, broadly, that supervisors must be certified educators or licensed psychologists (e.g., California State Senate, 1997). The licenses or certifications that exist for educators and psychologists in many states do not guarantee, or even promote, qualifications in behavior analysis. For these reasons, professionals in behavior analysis have begun to more assertively advocate certification of behavior analysts on a state-by-state basis and through a na-

tional program (Shook, 1997b). The key issue here is that professionals are seeking certification as a one means to assure that children with autism and related disabilities receive competently delivered state-of-the-art services (Autism Special Interest Group, 1998; Van Houten, 1994). The issues in special education extend to services for other populations of people with disabilities, including school-age children and adults, but services to preschoolers with autism is a critical arena for policy action. As David Roll noted in a recent issue of the New York State Association for Behavior Analysis newsletter, "At this point the demand and supply problem is so great that families and school systems are too frequently spending valuable resources for behavior analytic services by people who are minimally qualified to provide those services" (Roll, 1997, p. 1).

Certification will involve a great deal more action by behavior analysts than administering a test and encouraging successful individuals to establish programs and provide services (Shook, 1997a). To establish a certification program, the support and active advocacy of parents and other citizens concerned with the obligation of schools and public agencies to promote high-quality and relevant services will be required. Professional standards and a code of ethics will need to be established. Conferences of the Association for Behavior Analysis, state and regional affiliates, and other interested organizations will have to become venues for continuing professional education. Professional training programs in psychology and education at the undergraduate and graduate levels will have to be encouraged to offer pertinent courses that make students eligible for eventual certification (e.g., Hopkins & Moore, 1993; Jacobson, 1997). These all represent large undertakings, but at this juncture it seems that the threats to competent care for especially vulnerable children require that no less be done.

In addition to the efforts of profes-

sionals, parents have contributed to the development of better services in at least two ways. One is the demand for accountability in educational services. The second, together with professionals, is to promote competence in services for vulnerable and needy children.

The messages posted on Internet sites and lists suggest that on the one hand, parents want assurance that the people who are teaching their children have the necessary skills. On the other hand, parents are also concerned that certification or other regulations will greatly limit the numbers of qualified supervisors and trainers, and that trainers whom they now employ and who seem to be effective will not be qualified to continue serving children. However, at the level of policy, one of the reasons that many families are paying privately for these services is that there are no procedures to qualify people for payment from Medicaid or local educational agencies.

Some behavior analysts have been active in working with parents to influence rules or regulations as they develop in the area of early intensive behavioral services. In Wisconsin, for example, Medicaid rules for early behavioral intervention were developed in response to parental requests for services of qualified practitioners as supervisors of in-home early intensive services (e.g., Wisconsin Division of Health, 1997), and professional behavior analysts participated in advising the State of Wisconsin on the development and particulars of the rules. In California, parents and behavior analysts have been active in seeking changes to proposed legislation that would establish requirements for reimbursement in nonschool settings that provide intensive behavioral intervention services (e.g., related to California State Senate, 1997). In Alabama and New York, representatives of state affiliates have been discussing benefits and requirements of behavior analyst certification with government officials, involving behavior-analytic services. The partic-

ular forms of services that emerge in these different states will be related to past service-development practices, financing practices, and the effectiveness of joint advocacy and demonstration of service effects by parents and professionals working together (e.g., Jacobson, Mulick, & Green, 1996). In these joint efforts, professionals bring to the table the skills and technical knowledge needed to develop regulations that are not contrafactual in their requirements (Jacobson & Otis, 1992), whereas parents and family members provide a level of credibility and strength in numbers that providers and professionals cannot bring to bear within the political arena.

### **BEHAVIOR ANALYSTS, PARENTS, AND QUALITY CONTROL: A CONCLUSION**

In addition to joint efforts of parents and professionals to enhance access to high-quality services, it also seems clear that professionals have a role in assisting parents to become more adept in distinguishing between posers and professionals and more fluent in identifying which provider agencies and professionals are providing high-quality services (e.g., Crandall et al., 1997). Discrete-trial and applied behavioral services are very intensive and individualized services that require both knowledge and experience. Yet, as some parents have observed in Internet messages, they often encounter professionals who do not give them straight, clear, and responsive answers to their questions, who do not tell them about alternatives to the services they get, who do not know about the relative benefits that have been found for alternatives, and who are involved in what parents call watered-down services in schools, based on no more than 2 or 3 days of training for staff. Parents should be able to expect and get more.

What should parents expect from professionals who purport to provide applied behavioral services? Certainly



they should expect that these people will be forthright about their approach or the approach that their program or agency had adopted, what the basis of this approach may be, that they will provide parents with reference materials, research reports, books, or program materials that substantiate the approach that is being used, and that they will describe their training and qualifications and discuss fully any decisions with which the parents disagree. One parent wrote in an E-mail message,

In interviewing an agency, I'd ask to see their program progression (although all children are different, there should still be an idea of a master plan of getting a child from the beginning through to school), I would be wary of programs that are "making it up as they go." . . . I'd ask to speak to parents whose children are in the program, and parents from other programs. And I'd ask to see their data.

In general, parents appear to obtain the types of services for their children that they are willing to accept. This seems clear from the number of successful challenges of school districts in due process hearings to obtain behavior-analytic services for children (LRP Publications, 1995, 1996a, 1996b), although parents are not consistently successful in obtaining the desired services by this means. Many professionals in behavior analysis are committed to providing the best possible, comprehensive, and intensive early intervention services to children with autism. The capability to do this, and where and when the services are needed, however, will be established only if parents, rather than professionals, insist that schools and early intervention programs change their policies and practices, and assure that the people who provide early intervention services are competent to provide the specific types of services that are empirically validated as benefitting these children (Dorman & Long, 1999). Continued collaboration by professionals, in assisting parents in identifying critical elements of high-quality services and encouraging organized local advocacy for such services, will be critical to

achieving improvements in the therapeutic capacity of early intervention, preschool, and educational services. One parent advocate for children with autism, a very active FEAT member recounted, "A reporter recently asked me if I could have anything, what would it be? My reply was \$200 million in research [a reference to a pending federal funding initiative in autism], and for public school officials to stop patronizing me and my family. In retrospect, the latter is the more important."

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## APPENDIX A

**Federal requirements and representative cases regarding autism/PDD applied behavior analysis services in educational contexts**

Pertinent Federal Requirements Regarding Early Intensive Behavioral Intervention <sup>1</sup>	
<p>Individuals with Disabilities Education Act ("IDEA"); at 20 USC. § 1400, regulations at 34 CFR § 300. Section 504 of the Rehabilitation Act; at 29 U.S.C. § 794 with regulations at 34 C.F.R. § 104</p> <p>Family Educational Rights and Privacy Act ("FERPA"); at 20 USC. § 1232g with regulations at 34 CFR. and § 99</p> <p>Americans with Disabilities Act ("ADA"); at 42 USC. § 12101 with regulations at 28 CFR § 35.</p> <p>Technology Related Assistance For Individuals With Disabilities, at 29 USC Sec. 2109</p>	
Representative Cases in Which Parents Prevailed <sup>2</sup>	Representative Cases in Which Schools Prevailed <sup>2</sup>
<ol style="list-style-type: none"> <li>1. D. PL 1993: Delaware County Intermediate Unit ~ Martin L, 831 F. Supp. 1206</li> <li>2. SEA CA April 4, 1994; Calave-as Unified ScA. Dist.</li> <li>3. CA Aug. 15,1994; Mill Valley Ele Sch. Dist.</li> <li>4. SEA CA Oct. 23,1995; Capistrano Unified Sch. Dist.</li> <li>5. SEA GA May 30, 1996; Georgia SEA</li> <li>6. SEA IA May 31, 1996; Allamakee Commun. Sch. Dist. and Keystone AEA</li> <li>7. SEA MI. June 20, 1996; Bd of Educ. Of Ann Arbor Pub. Sch.</li> <li>8. SEA MN Aug. 10, 1996; Independent Sch. Dist No 318</li> <li>9. SEA MI Dec 13, 1996; West Bloomfield Sch. Dist.</li> <li>10. SEA ME May 31, 1997; Portland Pub. Sch.</li> <li>11. SEA TX July 31,1997; Ade Indep. Sch. Dist.</li> <li>12. SEA MA Aug.11, 1997; Petersham Publ. Sch.</li> </ol>	<ol style="list-style-type: none"> <li>1. S.D. 1994; Sioux Falls Sch. Dist. V. Koupal, 526 NW.2d 248</li> <li>2. SEA VA Jan. 9,1995; Fairfax County Pub. Sch.</li> <li>3. SEA MI Jan. 3, 1996; Kalamazoo City Public Schools</li> <li>4. SEA MI Feb. 6, 1996; Kalamazoo Valley intermediate Sch. Dist.</li> <li>5. SEA NY Mar. 11, 1996; Bd. of Educ. of Greenwood Lake Union Free Sch. Dist.</li> <li>6. SEA NY July 24, 1996; Bd. of Educ. of Syosset Central Sch. Dist..</li> <li>7. SEA GA Aug.11, 1996; Cobb County Schools</li> <li>8. SEA PA Aug. 12, 1996; Barks County Inter. Unit</li> <li>9. SEA TX March 5,1997; Flour Bluff Indep. Sch. Dist</li> <li>10. SEA SG Apr. 15, 1997; Lexington County Sch. Dist.</li> <li>11. SEA WA July 21, 1997; Shoreline Sch. Dist.</li> </ol>

Notes: <sup>1</sup>Source is <http://mayerslaw.com>; <sup>2</sup>Source is Peper Martin Law Firm, <http://home.att.net/~D.FAMILY/Public/sat.html>; SEA = state education agency; USC = United States Code; CFR = Code of Federal Relations; PL = Public Law.

## APPENDIX B

**Disputes and the substance of decisions related to parental reimbursements for costs for autism/PDD applied behavior analysis services in educational contexts: 1988–1998<sup>1</sup>**

<p>1. SEA NY 1988. Warwick Valley Central School District, 509:270</p> <p>2. SEA TX 1988. In the Matter of Brooke P., 509:246</p> <p>3. SEA WA 1989. In re Christopher B., 401:313</p> <p>4. SEA NJ 1995. High Bridge Bd. of Educ., 24 IDELR 589</p> <p>5. SEA WA 1995. Peninsula Sch. Dist., 27 IDELR 381</p> <p>6. SEA CT 1995. In re Child with Disabilities, 23 IDELR 471</p> <p>7. SEA CA 1995. Capistrano Unified Sch. Dist., 23 IDELR 1209</p> <p>8. SEA PA 1995. Chester County Intermediate Unit, 23 IDELR 723</p> <p>9. SEA WA 1995. Peninsula Sch. Dist., 27 IDELR 381</p> <p>10. SEA MI 1996. Board of Educ. of the Ann Arbor Pub. Sch., 24 IDELR</p> <p>11. SEA MN 1996. Independent Sch. Dist. No. 318, 24 IDELR 1096</p> <p>12. SEA GA 1996. Cobb County Schs., 24 IDELR 1113</p> <p>13. SEA OR 1996. Columbia Regional Programs/Portland Sch. Dist., 24 IDELR 98</p> <p>14. SEA MI 1996. Board of Educ. of the Ann Arbor Pub. Sch., 24 IDELR 621</p> <p>15. SEA MI 1996. Board of Educ. of the Ann Arbor Pub. Sch., 24 IDELR 621</p> <p>16. 2d Cir. 1996. Still v. DeBuono, 25 IDELR 32</p> <p>17. SEA OR 1996. Columbia Regional Programs/Portland Sch. Dist., 24 IDELR 98</p> <p>18. 2d Cir. 1996. Malkentzos ex rel. MM v. DeBuono, 25 IDELR 36</p>	<p>1. Eligibility tied to developmental regression, need for structure.</p> <p>2. Regression not required before extended year services.</p> <p>3. District must pay for independent evaluation</p> <p>4. District must reimburse parents for past expenses of in-home, (ABA) therapy</p> <p>5. Procedural errors in district evaluation result in reimbursement</p> <p>6. Reimbursement allowed for home (ABA) program, but not parochial preschool</p> <p>7. Reimbursement awarded for costs of in-home behavior therapy due to improper placement of child with autism</p> <p>8. Reimbursement denied for discrete trial training program; IU's proposed placement was educationally beneficial</p> <p>9. Reimbursement for in-home (ABA) program awarded where district program denied FAPE</p> <p>10. 35-40 hours of (ABA) therapy awarded to child with autism, plus reimbursement for home program</p> <p>11. District program inappropriate; reimbursement for home (ABA) program awarded</p> <p>12. District program offered student with autism FAPE in LRE; Reimbursement for private ABA therapy denied</p> <p>13. District's placement inappropriate; parents entitled to reimbursement for at-home, (ABA) type program</p> <p>14. Failure to request IEE at time of disputed IEP did not preclude reimbursement</p> <p>15. For parents, failure to meet state standards not bar to reimbursement</p> <p>16. Like Part B, Part H services need not be provided by qualified personnel in order to justify reimbursement</p> <p>17. Parents entitled to reimbursement for independent evaluation.</p> <p>18. Petitioners did not meet standard for injunction entitling them to reimbursement for past ABA therapy</p>
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*Notes:* <sup>1</sup>Source is Autism Society of America, Virginia Peninsula Chapter, <http://www.geocities.com/~peninsulaautism/html/idelrs/reimbursements.html> (descriptions of case decisions are verbatim from this source except for parenthetical terms). SEA = state education agency; FAPE = free and appropriate public education, IEE = independent education evaluation, ABA = applied behavior analysis; DTT = discrete-trial therapy, ESY = extended school year, IEP = individual education plan, DDESS = Defense Department educational support services, LRE = least restrictive environment, IDELR = Individuals with Disabilities Education Law Reporter (publication) citation, Part H = IDEA early intervention services, Part B = IDEA preschool education services.

## APPENDIX B

## Continued

19. SEA GA 1996. Cobb County Sch. System, 24 IDELR 875	19. Procedural/substantive violations entitled parents to reimbursement for home (ABA) program
20. DOD 1997. In Re: G., 27 IDELR 451	20. DDESS program denied student FAPE; Reimbursement for in-home (ABA) program awarded
21. SEA TX 1997. Azle Indep. Sch. Dist., 26 IDELR 931	21. District failed to timely assess and identify 4-year-old with autism
22. SEA TX 1997. Flour Bluff Indep. Sch. Dist., 25 IDELR 1121	22. Failure to provide ESY (Extended School Year) results in reimbursement for costs of summer (ABA) program
23. SEA TX 1997. Azle Indep. Sch. Dist., 26 IDELR 931	23. Denial of FAPE results in reimbursement award for costs of in-home (ABA) program
24. SEA CA 1997. Old Adobe Union Elem. Sch. Dist., 7 IDELR 70	24. Inappropriate District Programs Result In Reimbursement
25. SEA NV 1997. Washoe County Sch. Dist., 27 IDELR 133	25. Parent not entitled to reimbursement for costs of In-home ABA... program
26. SEA TX 1997. Flour Bluff Indep. Sch. Dist., 25 IDELR 1121 and SEA NY 1997. Board of Educ. of the City Sch. Dist. of the City of White Plains, 25 IDELR 872	26. Parents not entitled to reimbursement for additional ABA instruction
27. SEA SC 1997. Lexington County Sch. Dist. Five, 5 IDELR 933	27. Parents not entitled to reimbursement for various expenses
28. SEA NC 1997. Henderson County Pub. Schs., 27 IDELR 435	28. Proposed district program appropriate; reimbursement for (ABA) program denied
29. SEA NV 1997. Washoe County Sch. Dist., 27 IDELR 560	29. Reimbursement for ABA... program denied where district IEP offered FAPE.
30. SEA CA 1997. Old Adobe Union Elem. Sch. Dist., 27 IDELR 70	30. Reimbursement for independent evaluations denied where district evaluations were appropriate
31. SEA MN 1998. Independent Sch. Dist. No. 281 (Robbinsdale), 28 IDELR 370	31. 4-year-old with autism and mental retardation required 40 hours of ABA instruction per week
32. E.D. Mich. 1998. Burilovich v. Board of Educ. of the Lincoln Consolidated Schs., 28 IDELR: 277	32. District IEP appropriate; Reimbursement for in-home DTT program denied
33. SEA SC 1998. Lexington County Sch. Dist. One, 27 IDELR 1182	33. District IEP provided FAPE; Reimbursement for home ABA program denied
34. SEA CA 1998. Ontario-Montclair Sch. Dist., 28 IDELR 232	34. District ordered to fund in-home, discrete trial training program of student with multiple disabilities
35. SEA MN 1998. Independent Sch. Dist. No. 281 (Robbinsdale), 28 IDELR 370	35. ESY denied student FAPE; Parents awarded partial reimbursement for home ABA program
36. SEA MN 1998. Independent Sch. Dist. No. 281 (Robbinsdale), 28 IDELR 340	36. In-home program along with classroom programs provided FAPE to 4-year-old with autism
37. SEA NV 1998. Clark County Sch. Dist., 28 IDELR 804	37. Parents awarded reimbursement for in-home, DTT program and IEEs
38. SEA MN 1998. Independent Sch. Dist. No. 281 (Robbinsdale), 28 IDELR 340	38. Reimbursement awarded for 30 hours of weekly ABA instruction