

## The Adverse Effects and Societal Costs of Denying, Delaying, or Inadequately Providing EIBI for Children with Autism. (2012)

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Abstract. This document was assembled after being contacted by the California Department of Insurance to answer three questions about Early Intensive Behavioral Intervention (EIBI). The first question pertained to the benefits of early intervention for children with autism as demonstrated through published research. This question was answered with the report titled “Analysis of the Evidence Base for ABA and EIBI for Autism” (Larsson & Cross, 2012). In Larsson and Cross (2012), the benefits of EIBI include reductions in autism symptom severity, improved adaptive functioning, and gains in a variety of domains crucial to autism treatment are presented. In this current report titled “The Adverse Effects and Societal Costs of Denying, Delaying, or Inadequately Providing EIBI for Children with Autism” two additional questions are addressed. Namely, the adverse effects on children and their families if EIBI treatments are denied or delayed; and the societal costs incurred when medically necessary treatment is not adequately and timely provided. This report therefore defines some of determinations by health plans that may be construed as denial of treatment or inadequate treatment provision and highlights through research predicted effects and costs of such adverse determinations.

Applied Behavior Analysis (ABA) is defined as the science of behavior change in which tactics derived from the principles of learning and behavioral theories are applied systematically to improve socially significant behaviors (Baer, Wolf & Risley, 1968). Methods from ABA have been demonstrated to be effective at remediating the core deficits of autism along with replacing the behavioral excesses characteristic of this disorder. As the provision of ABA services currently falls under the scope of health plans in California, providers of evidence-based ABA treatments are concerned that certain coverage determinations by health plans result in medically necessary treatments being denied or delayed. Some these determinations by health plans are believed to incur adverse effects on children and their families with irreversible long-term costs are as follows:

1. Arbitrary limits on the number of treatment sessions authorized
2. Arbitrary limits on the number of hours approved for assessment
3. Arbitrary limits on the number of hours per month of supervision of ABA services
4. Failure to recognize QAS Professionals (Behavior Management Assistant vendors) as supervisors of some elements of treatment provision
5. Failure to recognize evidence-based ABA treatment requires both direct and indirect supervision and treatment planning

While the list of concerns above is not exhaustive, it is sufficient to demonstrate that the determinations made by some health plans are resulting in medically necessary treatments being denied or delayed. To further substantiate the adverse determinations of health plans providers of ABA services in the state of California are contemplating reporting directly to DMHC the numbers of QAS Professionals that health plans are recognizing as supervisors of behavioral treatment. Larsson (2011) details the amount of supervision and roles provided by QAS Professional personnel in the published reports on EIBI. Additionally, in Larsson (2011) figure one demonstrates a significant reduction in autism symptomology as supervision hours are increased from an average of 7 to 24 hours per month. The denial of QAS Professional supervision by health plans will undoubtedly replicate Larsson’s findings and result in the chronic and severe symptoms of autistic disorder and lifelong disability for a great number of children. More on this topic will be presented later.

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The decision by health plans to not contract and reimburse QAS Professionals is but one of many determinations that result in children being denied effective treatment. These decisions have both adverse effects on children and their families and significant, irreversible societal costs. The purpose of this document is to elaborate further on the adverse effects and societal costs incurred when medically necessary treatment is denied or delayed.

Forty years of research indicates there is no uncertainty about ABA treatment effectiveness (Larsson 2005; Larsson & Cross, 2012). There is firm consensus about the effectiveness of ABA in treating individuals with autism. According to Keenan and Dillenburger (2011) the United States National Research Council has determined that Applied Behavior Analysis incorporates characteristics of effective interventions in educational and in medical treatment programs for children with autism. ABA researchers and practitioners have developed effective treatment protocols using principles of learning established by researchers over the last century. These individually tailored treatment protocols address socially relevant behaviors and the core deficits of autism. The effectiveness of ABA in the treatment of autism spectrum disorder was recognized by the following: The US Surgeon General (2000); The Supreme Court of British Columbia (2000); The California Department of Developmental Services (2002); The New York State Department of Health (1999); The Maine Administrators of Services for Children with Disabilities (2000); and the Department of Defense (2007). According to the advocacy group Autism Speaks, 32 states have passed legislation requiring ABA treatment to be funded through medical insurance. The beneficial effects of ABA treatment for individuals with autism are widely recognized and accepted.

The goal of Early Intensive Behavioral Intervention (EIBI) is to change the child's developmental trajectory such that the child's behavioral repertoire and rate of learning approaches that of a typical child. The intent is to provide treatment early in a child's life and build communicative, social, and adaptive behavioral repertoires to replace the pervasive deficits characteristic of children with autism. For many children, treatment results in functional communication skills and averts the extreme threats that aggressive and self-injurious behaviors pose to the individuals' development. For other children, EIBI leads to significant improvements in all domains of functioning and inclusion in general education settings as well as normal functioning as adults. Subsequently, inclusion in general education predicts development as an independent, productive member of society. In contrast, individuals with autism that have not received effective treatment mature into adults with a higher probability of communication deficits, higher probabilities of experiencing self-injury as a form of communication, and a higher probability of being the victim of abuse.

In the recent paper submitted to the California Department of Insurance (Larsson & Cross, 2012), numerous meta-analytic studies have demonstrated that EIBI programs are effective in improving cognitive skills, language skills, social skills, daily living skills, and reducing autism symptomology in children with autism (e.g., Peters-Scheffer et al., 2011). Denying or delaying treatment undoubtedly results in lifelong detrimental effects. Today researchers and clinicians know this to be a fact based upon past research that demonstrated delaying EIBI treatment beyond age 5 for individuals diagnosed with autistic disorder does not produce the same significant gains in developmental outcomes (Fenske, Zalenski, Krantz, & McClanahan, 1985). Knowing the detrimental effects of delaying effective treatment, expert consensus advocates that treatment begin as soon as possible as there appears to be a window of time in which treatments seem to be maximally effective resulting in lifelong determinants of adaptive functioning (Rogers, 1996; Lovaas & Smith, 1988). The potential for negative effects of denying or delaying treatment has also resulted in recommendations to begin treatment as soon as a preliminary or provisional diagnosis of autism is rendered (American Academy of Pediatrics, 2001; The California State Department of Developmental Services, 2002; DMHC Autism Advisory Task Force, 2012).

### **Financial Cost Benefit Analyses**

Cost benefit analyses of early intervention ABA therapy have found that the cost savings substantially exceeds the early intensive treatment cost for a 3 year old child with autism or ASD (Columbia Pacific Consulting, 1999). The authors found a home-based program to be less expensive than alternative non-ABA based special school placements (Peach 1997). In Ontario Canada, savings of over \$45 million per year (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006) resulted in Canada's widespread decision to offer intensive behavioral intervention routinely to people diagnosed with ASD.

In the United States researchers John Jacobson, James Mulick and Gina Green provided a cost benefit analysis for early intensive behavioral interventions (EIBI) for young children with autism in the State of Pennsylvania. Their 1998 analysis estimated cost savings from \$187,000 to \$203,000 per child for ages 3-22 years, and from \$656,000 to

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\$1,082,000 per child for ages 3-55 years.. The authors suggested that significant cost aversion or cost avoidance was possible with EIBI.

Researchers have shown that without effective intervention, individuals with ASD and their family require lifelong support services at a cost estimated at \$4 million in some states. Millions of dollars are spent on treatments of little demonstrated efficacy. ABA based treatments are effective, however it is important to determine how ABA treatment is likely to pay off with respect to children, to families and in financial savings.

Guralnick (1998) and Ramey and Ramey (1998) describe essential components of effective ABA interventions. These components are:

1. emphasized skill development through positive reinforcement;
2. started with an assessment of each child's current skills and deficits; instructional objectives, teaching methods, pacing, skill sequences, and reinforcers were all customized to the characteristics and needs of each child;
3. addressed all skill domains and provided treatment intensely for a period of years;
4. used frequent direct observation and measurement of individual performance to determine if progress was occurring, and adjust instructional methods accordingly;
5. included parents as co-therapists; and
6. were directed by individuals with postgraduate training in behavior analysis and supervised by individuals with post-Bachelor's training plus extensive hands-on experience in providing ABA intervention to young children with autism.

Lovaas and others (Lovaas 1987; McEachin, Smith, & Lovaas 1993) found that 47% of the children receiving EIBI were able to function independently and successfully in regular classrooms. Another 40% improved but continued to need specialized intervention and about 10% made minimal gains.

#### Cost Benefit Analysis of EIBI

Jacobson et al., (1998) estimated the financial costs and benefits of EIBI using information from the State of Pennsylvania. The major assumptions were:

1. There is insufficient scientific evidence on which to base predictions about the likely outcome for any individual child.
2. In any group of children receiving EIBI, between 20% and 50% will achieve normal functioning and require no specialized services after entering elementary school. About 10% will make small gains and require intensive special education and adult services (minimal effect group). The remainder will make moderate gains and need non-intensive special education and adult services (partial effect group).
3. Without EIBI, most people with autism need lifelong special services.
4. The average duration of EIBI is estimated to be three years.
5. Children who realize partial or minimal effects will use family support services to age 22, i.e. for 18 years.
6. During adulthood, those who achieve partial effects will use 18 years of Medicaid waiver (or equivalent) services and 15 years of supported work services.
7. During adulthood, of those adults for whom minimal effects are obtained, 80% will use waiver services for 20 years, 20% will use intensive community services for 23 years, and 40% will use supported work services for 15 years.

According to the Jacobson et. al., (1998) the authors "summed the costs of all public entitlements to early intervention, education, family support, adult services, and Social Security benefits for people with autism. Then, factored in earnings in adulthood using the 1996 median household annual income to estimate earnings by individuals who are diagnosed with autism or PDD as young children but achieve normal functioning by adulthood, and supported employment wages for those who do not".

[What follows is from Jacobson et.al. article in Behavioral Intervention, 1998, Volume 13, 201-226.

## Summary of Results

Table 1 Estimated Net Costs and Savings of EIBI, Ages 3-55 years.

Net Savings for typical Developing person	\$1,597,049
Net Savings for child with autism/PDD who achieves normal functioning	\$1,475,791
Net Cost for child who realizes partial effects	\$3,368,469
Net Cost for child who makes minimal gains	\$4,404,482
Net Savings for child who realizes partial effects (\$4,404,482-\$3,368,469)	\$1,036,013

The net savings for a typically developing person shows the cost benefit of providing public education K-12 to a typically developing person through adulthood, i.e., career income minus costs of education. The net savings for a child with autism/PDD who achieves normal functioning has a similar basis, except that costs for early intervention and preschool age support services are included. The net cost for a child with autism/PDD who makes minimal gains is the cost of services for 52 years, less income from supported work. Net savings to age 55 for a child who achieves partial effects are the difference between “minimal gains” costs and “partial effects” costs. Below we show the range of average weighted cost benefits (savings) per child, based on differing levels of effectiveness of programs, per hundred children. For this reason, the savings we show below cannot be calculated directly from the costs shown in Table 1. The steps used to estimate these ranges are shown in the full article.

**Estimated savings per child, 3-22 years.** Average savings to the educational system range from \$298,651 to \$274,709 depending upon the proportion of children - 20, 30, 40 or 50% - who achieve normal functioning levels. Surprisingly, because children who achieve normal functioning continue to incur costs throughout the school years, i.e. the costs of regular education services, the largest savings actually come from the children who achieve partial or moderate gains from EIBI. This aspect of savings is not shown in Table 1 but is shown in the full article. The average cost savings are roughly equal to total regular education costs in Pennsylvania for a child from K-12.

**Estimated Savings per Child, Ages 3-55 Years.** The average savings per child to age 55, again depending on the proportions of effectiveness of EIBI, range from \$1,686,061 to \$2,816,535. There are a number of factors that cause the savings to be greater through adulthood. The most important considerations are that a person may use adult human services for a longer period of time than they attend school during their life span, and that some adult human services have annual costs higher than the annual costs of special or intensive special education.

## Discussion

Like effective treatments for other severe childhood disorders, such as cancer, early intensive behavioral intervention can be described as aggressive, intrusive, and necessitating a high level of specialized expertise for effective delivery. The decision to invest in intrusive, expensive treatment for childhood cancer is usually based on several factors, including the scientifically demonstrated efficacy of other treatments, and the probable consequences of pursuing other treatments or no treatment at all. If a child with a major disorder needs treatment, cost is usually not a major factor; various public and private resources are typically made available. Many parents and professionals are beginning to insist that the same considerations apply to the treatment of children with autism. We should all recognize that the most expensive interventions are those that fail to produce meaningful, measurable, lasting benefits, regardless of cost. While the focus on “costs” above has centered on the financial costs, there clearly are other costs associated with the provision or denial of treatment. Some of these costs are more easily assessed such as parental reductions in the symptoms of depression, anxiety, or increased likelihood for marital stability in families receiving EIBI (Cohen, et al., 2006). Other emotional, psychological, societal costs resulting from a denial of child’s medically necessary treatment are significantly more difficult to capture and quantify. The benefits of EIBI to the child and the family have been well documented and are the continued topics of refined research to date. Currently, financial cost analysis fully demonstrates the long-term savings that can be realized with the adequate provision of EIBI treatment for children with autism.

## **The adverse effects on children and their families if ABA treatments are denied or delayed**

Autism is a severe, chronic, developmental disorder that results in significant lifelong disability for most persons. While it was once believed that autism was untreatable (DeMyer, Hingtgen, & Jackson, 1981), current research has demonstrated the effectiveness of EIBI in treating autism. Given the demonstrated effectiveness of EIBI/ABA, research on delaying or denying treatment would be ethically prohibited for a Board Certified Behavior Analyst to conduct. Therefore there are no recent studies that explicitly addressed the outcomes for individuals with autism that were intentionally denied treatment.

Some historical research does however highlight the effects of denial or delaying treatment. In Lovaas et al. (1973) the researchers found that the younger children acquired greater communicative skill, play skills, social skills, and demonstrated greater reductions in aberrant behavior as compared to older participants. Therefore the UCLA young autism project sought very young children (average age of treatment initiation was 34 months) to be enrolled in their treatment program subsequently published in Lovaas (1987). Additionally, this study contained two control groups, one that received “treatment as usual” and one that received minimal behavioral treatment. The progress between the groups was significant with 47% of the EIBI group demonstrating gains in language and communication, intellectual functioning and gains in adaptive behavior so profoundly that the diagnosis of autistic disorder no longer was appropriate. Gains such as these were not demonstrated by children in the control groups and therefore if medically necessary treatments were denied or delayed we should expect the outcomes of children to resemble those participants in the control groups. Clearly, ethically and professionally we cannot deny children their right to effective treatment for autism.

Similarly, Fenske, et al., (1985) demonstrated differential effects of treatment for those children who began prior to age 5 versus those for whom treatment was delayed to after age 5. The researchers found significant differences in outcome between those children for whom treatment began later and as such, the field of autism research has advocated for early initiation of treatment between the ages of 2-4 (Rogers, 1996).

One can additionally reference the developmental outcomes of individuals with autism that appeared in wait-list, control, or eclectic treatment conditions in treatment comparison studies. Numerous meta-analyses have done so (see Larsson & Cross, 2012) and demonstrated significant effect-size gains in adaptive behavior and intellectual functioning (e.g., Eldevik et al., 2009). Additionally, other autism specific outcome measures including language, communication, and a reduction autism symptom severity have been demonstrated as a result of participants receiving EIBI (Rogers & Vismara, 2008).

EIBI is a complex and multifaceted treatment approach and unfortunately all of the elements of an EIBI program are not as well known in comparison to our knowledge of other medical treatments. For example, cancer may be treated with a combination of radiotherapy, chemotherapy, and surgical resection of the primary tumor. For some types and stages of cancer, this combination of radiotherapy, chemotherapy, and surgery is widely accepted as the treatment of choice based upon published research on survival rates and expert consensus. Now if a health plan were to uniformly begin denying coverage for any one of the components (e.g., chemotherapy) there would be outrage expressed from patient and physician groups alike until the coverage determination was reversed. Unfortunately in the field of EIBI in California, many health plans have made determinations not to contract and reimburse for the direct and indirect supervision provided by QAS Professionals. The following section will detail the medically necessary elements of EIBI treatment, quantify the contributions of QAS Professionals in the published research on EIBI, and highlight some research detailing the adverse effects of denying supervision provided by a QAS professional.

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## Medically Necessary Elements of EIBI

When discussing the evidence base for Applied Behavior Analysis in the treatment of autism, most sources cite 40 hours per week as a significant measure of treatment intensity (Myers, et al., 2007). However, it is critical to understand an important feature of the research: While the research to date has most often defined intensity by counting the number of one-to-one hours that the child receives, the actual composition of the treatment service is much more complex. The complexity is a necessary component of the treatment that is proven effective. In particular, beyond the simple descriptive measure of 40 hours per week, the number of clinical supervision hours, planning hours, training hours, co-therapy hours and team meeting hours are crucial for ensuring that this treatment is sufficiently individualized to be medically necessary and cost-effective.

### CRITICAL COSTS OF THERAPY

The following costs of therapy were integral parts of the long-term outcome research from studies such as: Lovaas, 1987; Sallows, 2005; and Cohen, 2006. These research studies are associated with the greatest gains in children with autism, with 26-47% of children obtaining reduced symptomology, average intellectual functioning and completing first grade in a regular education classroom without support from an aide.

- Intensive Parent Training
- Co-therapy sessions
- Clinical review meetings with all therapists and parents present
- Certification process
- Individualized Program Design
- Therapy Material Creation
- Travel Time Between Homes
- Data Summary and Analysis

### **Intensive parent training**

One goal of Early Intensive Behavioral Intervention (EIBI), which most parents expressly seek, is to recover the child from the symptoms of autism (Maurice, 2001). One proven model of recovery-oriented treatment requires extensive parent involvement in a complex and dynamically changing treatment plan over a period of time that ranges from 18 months to five years for most cases (Lovaas & Smith, 2003). When providers do not share such goals, it is reasonable for them to gain the parents' consent for eclectic or lesser intensity services. But parents should be well informed that it also clearly proven in research that services which do not demand of the parents that they engage in effective therapeutic skills 24 hours a day, seven days a week, are unlikely to result in the kind of recovery that they should expect from the expense of intensive treatment (Leaf, Taubman, & McEachin, 2008).

The most central focus of this comprehensive therapy is the family therapy. In each family's case, extensive support and parent training is required, not just to train the parents to rationally use therapy skills, but also to support them in emotionally adopting new parenting behavior (which is in direct conflict with their history of parenting and long-term family history). Helping a parent to effectively follow through with therapy at the checkout counter, in the car, at the doctor's office, at meal time, during a play date, at bedtime, at the grandparents' party, etc. is extremely challenging. In effective EIBI, the parents are not just responding effectively to a tantrum or other dangerous behavior, but they are also teaching social language skills at the same time, in embarrassing public situations. Further, the mother and father are not typically working together consistently when therapy begins, and their own conflicts must be addressed. Most typical families muddle through such difficult times and their children develop typically, because they are not afflicted by autism. However, if the goal of treatment is to change the very autistic symptoms that stand in the child's way of typical functioning, then families cannot succeed without extensive emotional support and skill-training expertise.

Parents do not change their emotional behavior easily. They require frequent direct supervision by sophisticated staff, during every aspect of therapy, in order to effect change. In addition, they require frequent parent-training co-therapy with a senior behavior therapist who is narrating and instructing them while they observe the model of a behavior therapist working effectively with their child. In many cases, they also require separate direct counseling by the supervisors while a behavior therapist is managing their child, simply to be able to focus on the issues at hand without constant distractions.

As part of this extensive and necessary comprehensive family skills training, the provider would also conduct a weekly review with the parents and all staff involved. This clinical review "meeting" is essential to the continuity of care of the treatment plan, by providing simultaneous direction to the parents as well as the staff, and much specific family skills

training is done in this “meeting” every week. Finally, this meeting serves as an review meeting on a weekly basis to ensure that the family is fully and genuinely informed of the latest treatment recommendations, goals, and procedures. Their successful training in the meeting is part of their weekly consent to the treatment.

### **Co-therapy sessions**

Lovaas 1987 was conducted with “an average of 40 hours, with frequent co-therapy” (Leaf, Taubman, & McEachin, 2008). Sallows 2005 was conducted with “a senior therapist [who] delivered 6 to 10 hours per week in 3 co-therapy sessions per family.”

Co-therapy sessions allow for a number of clinically necessary activities to take place. First, they ensure treatment fidelity by allowing therapists to observe and critique the work of their peers. Second, they allow for maximum use of therapy time. One therapist can set up a structured program or record data while another therapist plays with a child and utilizes incidental teaching techniques. Third, they permit teaching through observational learning. One of the most crucial skills for a child with autism to learn is how to learn from others. Typically developing children readily seek out other children, insightfully recognize the intent of their behavior, and learn by imitating it. Co-therapy allows for one therapist to engage in play at a child’s current level while the other therapist prompts and reinforces the child’s imitation. Finally, co-therapy allows for greater parent-therapist interactions in which parents have more opportunities to learn through modeling and feedback. With only one therapist present, it is difficult for a parent to ask questions in the moment without interrupting or taking away from therapy time. A second therapist has the advantage of narrating and instructing parents while they observe the model of a behavior therapist working effectively with their child. This modeling is one part of effectively teaching parents to implement the same procedures throughout the remaining hours of the day when a therapist is not present.

### **Team meetings with all therapists and parents present**

Lovaas, 1987; Sallows, 2005; and Cohen 2006 all included a minimum of a weekly team meeting at which all staff and parents were present. This “meeting” is essential to the continuity of care of the treatment plan, by providing simultaneous direction to the parents as well as the staff, and much specific family skills training is done in this “meeting” every week. Finally, this meeting serves as a review meeting on a weekly basis to ensure that the family is fully and genuinely informed of the latest treatment recommendations, goals, and procedures. Their successful training in the meeting is part of their weekly consent to the treatment.

### **Certification process**

Lovaas, 1987 notes “Typically, new staff worked alongside a more experienced staff member for several weeks” and were “supervised by a graduate student in psychology or an advanced undergraduate student.” Sallows, 2005 notes “Therapists received 30 hours of training, which included a minimum of 10 hours of one- to-one training and feedback while working with their assigned child.” Further, “senior therapists...were required to meet quality control criteria set at UCLA. This involved passing two tests. The first was a written test designed to assess knowledge of basic behavioral principles and treatment procedures described in *The Me Book* (Lovaas et al., 1981). Second, they were required to pass a videotaped review of their work (conducted by Tristram Smith, research director of the Multi-Site Project, who used the protocol described by R. Koegel, Russo, and Rincover, 1977).” Cohen, 2006 notes “Tutors had to pass a rigorous behavior observation assessment of their accuracy in conducting discrete trial training (DTT) and oral tests of their knowledge of the UCLA treatment manual.” Further, “To become a supervisor, individuals had to meet prespecified, objective criteria, including high ratings based on direct observation of their implementation of EIBT interventions, favorable evaluations from families and staff members, satisfactory performance on a test of skill at curriculum development, and oral and written demonstration of their knowledge of applied behavior analysis and ASD.”

While standards such as those required for national certification through the Behavior Analyst Certification Board have helped prepare individuals to implement ABA therapy, the fact remains that a large majority of training continues to be carried out through a pyramid training approach that has a lengthy and well-regarded history in the field of community psychology. In short, those who are interested in gaining experience and competence in our treatment first gain valuable field experience by providing one-to-one treatment to a child with autism. Training is overseen by qualified behavior analysts. Therapists have the opportunity to progress to different levels of supervision in which they begin to train others in the techniques they have learned, oversee a child’s progress, and eventually design programs for a child. Not all therapists progress to these levels as strict performance criteria must be met in order for someone to be considered competent at each level. In all, it typically takes a minimum of two years before someone reaches a level at which they begin to learn to design programs for other children under close supervision of trained professionals at the

Institute. The amount of time required to master each level again points to the complexity of a good behavior therapy program.

### **Individualized Program Design**

Because the therapy is complex and many faceted, we must use a high level of expertise with a significant level of training and supervision. We make regular clinical judgments on a minute-by-minute basis, rather than following a stale written plan. Therefore we emphasize a system with delivers high-quality decision making. We use complicated information and analysis to make the best choices for the short term and for the long term. Each child presents a unique set of challenging behaviors and skills, and requires highly individualized planning on a weekly basis in order to make progress. This planning may include consultation with other behavior analysts, research in relevant journals, and review of similar cases from the past.

As just one example, Cohen 2006 states, "During the course of the study, there was a growing recognition that many children who made significant gains in the first 2 years of treatment required training beyond the UCLA curriculum to develop mutually satisfying social relationships, enhance their understanding of social meanings, understand and interpret other's perspectives/ knowledge/cognition/beliefs, and ultimately respond appropriately to social behaviors of peers and others. To address this need, overt social behaviors were operationally defined, both verbal (e.g., conversational skills, such as responding to statements or questions asked by others, reciprocal statements, initiating conversation, inquiring about others, remaining on topic, and sustaining conversation) and non- verbal (e.g., interpreting and responding to other's facial expressions, emotional states, voice tone, or body language), and initially taught in a discrete trial format, using the same behavioral principles and methodology described above, with an emphasis on a quick transition to generalized teaching to a social context, using incidental teaching and video modeling as tools for generalization."

### **Therapy Material Creation**

As a result of the individualized nature of treatment, many therapy materials are not readily available for purchase, but rather require creation by a therapist or supervisor. Some children with autism either need to start with or continue to do better with requesting when using real life pictures of their food, drink, and toys rather than using a more abstract PECS symbol. It's often helpful to teach emotions and actions using pictures of parents, siblings, and teachers – the individuals with whom the child is likely to see the emotions – rather than generic emotion cards. In order to facilitate generalized responding as well as counter overgeneralization, multiple exemplars are often needed of the same picture (for example, a boy with a red hat holding a green flower, a girl with a red hat holding a green flower, a boy with a blue hat holding a yellow flower, etc.).

### **Travel Time Between Homes**

Lovaas, 1987; Sallows, 2005; Cohen, 2006 were all studies with therapy that initially occurred completely in the home setting. Sessions often lasted for two to three hours with a one or two hour break between sessions and rotation of staff. The home setting is the primary place that a young child learns. It offers access to materials the child will come in contact with later in the day. It allows parents continuous access to the procedures that are being used in treatment. And it allows parents immediate recognition of new skills their child has learned that can be reinforced at other times of the day. The rotation of staff provides the child with multiple role models and decreases the likelihood the child will become prompt dependent on one therapist. All of these benefits greatly increases the likelihood of the transfer of skills and knowledge to other environments and with other people.

### **Data Summary and Analysis**

Lovaas, 1987; Sallows, 2005; and Cohen, 2006 included programming decisions that were based on a child's data. A hallmark of applied behavior analysis in general is its collection and use of observable data to guide treatment decisions. The large amounts of data that are collected on a daily basis must intermittently be summarized, tabulated, or graphed in order to display the noticeable trends and changes in behavior that may require a new plan of action.

### **Other Costs of Therapy**

In addition to all of the above, let's not forget the common and appropriate administrative overhead (not only in terms of an office, but also in terms of salary, health benefits, vacation time, etc.) that a company would also incur in order to maintain a well-trained staff.

While all of the above elements of EIBI treatment are not as well known by the public, they are never less medically necessary in order to obtain the autism symptom reductions and gains evidenced by children in published reports of

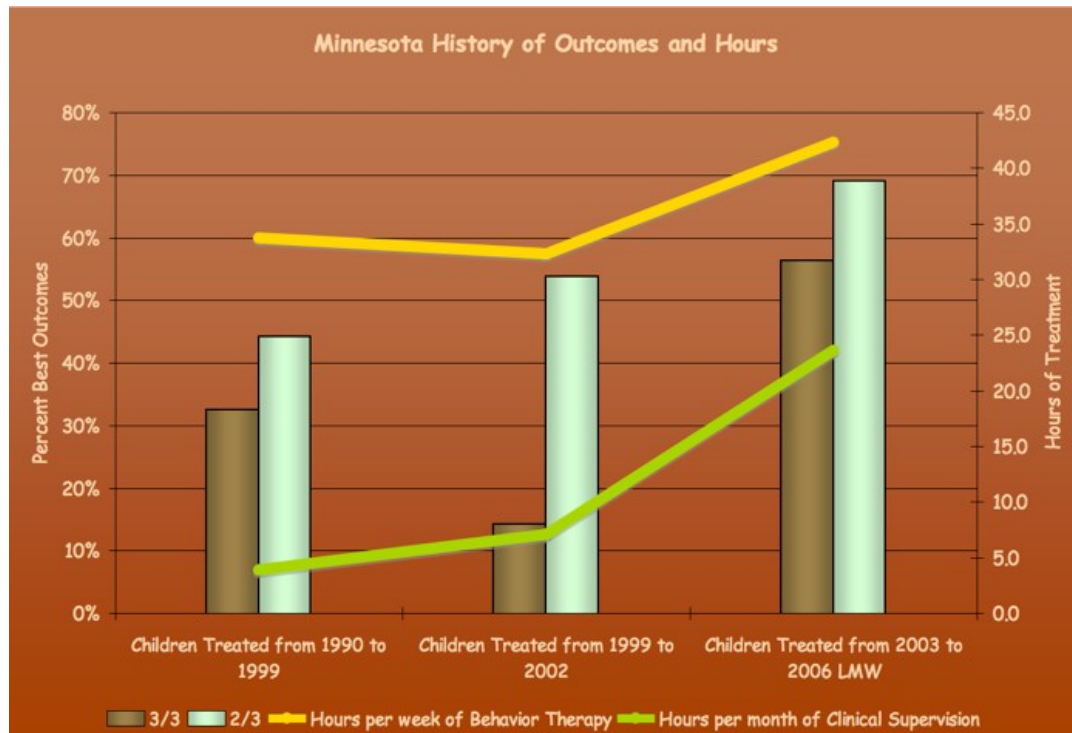


EIBI treatment. Once again a pyramidal approach to treatment supervision is the process by which evidence-based treatments have been delivered by individuals with primarily Bachelor's degrees and significant competency-based training. Within SB 946, the QAS Professional most closely aligns with the middle tier of supervision provided in published research. In published research varying titles such as clinical supervisor, program consultant, or senior tutor have been utilized to describe the QAS Professional level. Despite the nomenclature differences, the roles are similar entailing review of direct observational data, ongoing performance feedback to para-professionals, parent training, direct observation of treatment, modeling of treatment procedures, and modifications to the comprehensive treatment plan. Supervision provided by Bachelor's level personnel is underlined in the Table 1 below.

Study	Level of Additional Supervision	Frequency of Clinical Review Meetings
Lovaas, 1987	Daily to weekly direct supervision by direct <u>supervisor</u> , and <u>clinical supervisor</u> , and psychologist.	Weekly team clinical review meeting
Cohen et al., 2006	<u>Clinic Supervisors</u> provided ongoing performance feedback and weekly parent training.	Weekly team clinical review meeting & six-month clinical review
Sallows & Graupner, 2005	6 to 10 hours of weekly co-therapy by the <u>senior therapist</u> and weekly supervision by the <u>clinic supervisor</u> .	2 weekly team clinical review meetings
Eikeseth et al. 2002, 2007	10 hours per week of apprentice observation and supervision by <u>supervisors</u> , weekly supervision by project directors. 4 hours per week of parent training.	2 hour meeting weekly
Hayward, et al. 2009	5 hours per week of <u>programme consultant</u> supervision. 11 hours per week of <u>senior tutor</u> supervision. 2 hours per month by programme director. 2 to 5 hours per week of parent training.	2 hour meeting weekly

The contributions of Bachelor's level QAS Professionals in the delivery of EIBI are substantial. Failure of a Health Plan to recognize the QAS Professional in their contracts is likely to result in numerous adverse effects. These adverse effects can be examined by investigating the published reports of EIBI in which the supervision provided was low and not adequate to address all of a child's medically necessary treatment needs.

The impact of low versus intensive supervision in Minnesota. In the history of ABA treatment in Minnesota, the following results were found. In the 1990's a single behavioral psychologist's caseload averaged 60 families, and each family received about 4 hours per month of clinical supervision. Then, as a result of advocacy, from 1999 to 2003, providers were able to increase the amount of BCBA-level supervision to 7 hours per month, and slowly start more professional training of staff, but the level of recovery remained about the same. However, as of 2003, the Lovaas Institute in Minnesota instituted rigorous case-management, training, and supervision standards, and families were able to receive an average of 24 hours of clinical supervision per month. As a result the rate of best outcome grew to exceed 50%. Best outcome was defined as significant symptomology reduction resulting in the diagnosis of autistic disorder removed, average standardized assessment scores, and inclusion in general education first grade classroom without specialized supports. Children who met 3/3 of these best outcome criteria are represented by the brown bars. (See Figure 1).



#### Research on treatment with low levels of supervision

For comparison purposes, Leaf, Taubman, & McEachin (2008) summarized the components of high intensity supervision as follows: Staff hired and trained by agency; One to two months of pre-training; Weekly and sometimes daily supervision; Weekly Clinical Review Meetings; High level of expertise in Clinical Supervision. In contrast, they summarized low intensity supervision as being comprised of: Staff hired by parents; Staff trained through consultation; Three days of pre-training; Monthly to quarterly consultation; Monthly to quarterly Clinical Review Meetings; Poorly controlled supervisor expertise. In comparison to the high intensity studies reviewed above, several studies of low intensity supervision have also been conducted. In each of these studies, the levels of recovery from autistic symptoms have been much less (Smith, Buch, & Gamby, 2000; Smith, Groen, & Wynn, 2000; Remington, et al., 2007). In some reports of early intervention where limited gains were found (Bibby, et al., 2002; Magiati, et al., 2007), the reported levels of supervision have been as low as only once every 3 months. Therefore denial of QAS Professional supervision is likely to replicate the findings of low intensity behavioral treatment with significantly fewer reductions in autism symptom severity. Once again, there appears to be a critical window of opportunity for children with autism and by denying the evidence-based QAS Professional supervision in the amounts provided in Table 1, the adverse effects of increased symptomology and lack of developmental gain will result in lifelong, irreversible disability. Failure of Health Plans to recognize the QAS Professional results in a system of inadequate treatment provision for which no remedy currently exists.

### IN SUMMARY

The goal of intensive early intervention, which the child's parents seek and consent to, is to remediate the child from the symptoms of autism. Without adequate services, the front line staff will be making the kinds of rote programming errors and using inappropriate punishment procedures that cause harm to the child (either directly or by precluding their chance of recovering a successful developmental trajectory). Reviewing both historical research and contemporary research one can conclude that the adverse effects of denying or delaying medically necessary treatment would be to deny patients the right to effective treatment resulting in irreversible adverse effects. It is logical to conclude from the analysis above that when treatment is denied or delayed, the positive effects of treatment are not possible and debilitating effects of autism and PDD will continue to occur or may in fact exacerbate.

While a particular case was made in regards to the denial of QAS Professional supervision provide by Bachelor's level staff, similar arguments could be made for other coverage determinations made by Health Plans. For example, setting a session limit (for example 20) will likely replicate the control group outcomes in Lovaas (1987) in which low intensity treatment did not have an affect on autism symptomology, in contrast the significant effects of high intensity treatment. To date, meta-analytic research has determined that high intensity EIBI treatment (defined as 35 or more hours per week of para-professional treatment with QAS Professional and QAS Provider level supervision delivered in the amounts describe in Table 1) was the one and only predictor that accounted for both gains in adaptive behavior and cognitive functioning (Eldevik, et al. 2010). Therefore, replication of the beneficial effects of EIBI treatment will only occur if all of the elements that comprise the tiered or pyramidal delivery of EIBI are reimbursed by health plans.

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