Early Intervention Issues in Autism Spectrum Disorders

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Introduction

The pediatrician’s role in chronic management of Autism Spectrum Disorders (ASDs) is now recognized [1]. However, pediatricians and other primary care physicians typically receive little training in long-term behavioral interventions appropriate for these patients, an important medical home issue given that parents seek treatment advice from their child’s doctor. The target audience of this paper includes both physicians caring for children with ASDs and parents who wish to share this ASD behavioral treatment perspective with their child’s doctor. There are more than 25 states that have legally mandated that children with autism receive Early Intensive Behavioral Intervention (EIBI) as per the National Conference of State Legislatures [2]. The necessity of such legislation stems from difficulties families have had historically in obtaining evidence-based EIBI for their children with ASD, an important public health issue [1]. There is growing concern among physicians and families about how to improve the “medical home” for children with autism. Several helpful resources have been developed, yet are limited in addressing complex EIBI issues for physicians, who under new state laws noted above now have the responsibility for authorizing behavioral care such as EIBI. However, most physicians have limited training on behavioral services, especially EIBI. Families typically seek their pediatrician’s recommendations on what interventions to pursue and how to find them. Additionally, funders such as insurers may require referral and progress-monitoring from physicians. Of early intervention services, EIBI is one approach that has generated great interest and is the focus of this review manuscript.

In an effort to improve access to evidence-based treatment for autism and inform physicians and parents of children with ASD on treatment options, this article provides an overview of: a) essential components of EIBI, b) EIBI empirical literature and critical analyses; c) common misconceptions about behavioral interventions; and d) critical issues that affect patients’ access to EIBI. Bringing EIBI into the medical home is then summarized to highlight the importance of continuing medical education for physicians on treatment of children with ASDs in order to recognize the public health benefits of evidence-based approaches such as EIBI.

Essential Components of EIBI

EIBI programs involve an appropriate developmental curriculum, starting at the child’s developmental level and taught in small, progressive steps using evidence-based procedures derived from the science of Applied Behavior Analysis (ABA). EIBI follows a time-line of when to teach specific skills. The set of evidence-based strategies to teach a particular skill are termed as “program”.

EIBI is intensive, given multiple hours a day, 5 days per week, with breaks for play, naps and meals. Abilities are probed for initial skill-level in such areas as: play, readiness-to-learn (coming when called, toy play, sitting at a table, etc…), self-help skills, matching and sorting, non-verbal and verbal imitation, object and behavior labeling, commenting (on needs and observations), social language, peer play (facilitated play dates) and abstract, academic concepts (color, size, quantity, etc…). Skills are taught systematically in natural settings, such as home for a young toddler and a structured preschool-type environment for older toddlers. Many opportunities are created for the child to respond to specific tasks with repeated learning trials, while keeping data on response accuracy and prompts needed for success. Children are given immediate praise and other appropriate reinforcement, with the greatest reinforcement reserved for unprompted, correct responding. Gentle, effective error-correction procedures are used for the child’s errors. Programs should be closely supervised by a trained behavior analyst with years of experience working with children on the spectrum, who carefully analyzes performance data to guide programming decisions.

Quality EIBI meets developmental needs of the child and family, collects meaningful progress data and should show substantial, clinically significant progress for the child that improves functionality. Ideally, progress rate should allow the child to make catch-up gains toward neuro-typical development [3]. Treatment should be child-and-family-focused, aiming to minimize core autism symptoms and family stress while maximizing functional communication, independence and quality of life [1].

Parental involvement is strongly emphasized in EIBI. This allows parents to inform therapists on what reinforces their child, implement successful teaching strategies, reinforce skills taught and promote generalization of skills with other people, in other settings. There are extensive ABA publications on strengths and potential drawbacks of the teaching procedure called Discrete Trial Training (DTT), but DTT has consistently been important in the majority of scientific studies showing positive results of EIBI in autism [4]. DTT uses repetition for prompt-fading to promote independent responding), the child’s response (correct or incorrect), immediate feedback (reinforcement for correct response and error-correction for wrong response) and a brief pause by the teacher (inter-trial interval). DTT is highly effective to work for catch-up gains in learning [6-8] and is typically combined with natural-incidental and other teaching procedures. There are evidence-based treatments incorporating ABA principles that do not use DTT such as Pivotal Response Training [9] and the Early Start Denver Model [10], but their published evidence is not as great as for ABA treatments incorporating DTT. How much DTT children with autism should receive is debated but individual learning styles likely play an important determining factor [4].

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Integration of the affected child into regular preschool with behavioral support is important in EIBI. This provides for many socialization opportunities with typically-developing peers. Behavioral management involving a functional assessment of misbehavior is critical to remove instructional barriers. Pre-existing misbehavior does not preclude children from EIBI intervention, since misbehavior is effectively treated with ABA strategies [11-15]. Additional essentials involve starting early, soon after diagnosis, and high-intensity services. What high-intensity means is debated but scientific literature and national expert consensus suggests a minimum of 25 hours per week [16], while most studies support 30 to 40 hours per week [17-19]. The focus is on language acquisition, covering all important developmental areas and conducting intervention across all environments (home, preschool and community).

Skill training is critical for the child’s caretakers so that the family can help the child generalize skills. Parent-training on basic fundamentals at initiation of treatment improves overall treatment success [20]. Training includes instruction on the principle of reinforcement to strengthen behavior, removing reinforcement for misbehavior, effective use of prompting and shaping a skill and prompt-fading to avoid prompt-dependency. Parents are taught to break complex skills down into simple steps chained together until the child masters the task from start to finish. Continued parental training and involvement is vital throughout the duration of intervention.

EIBI Empirical Literature

The US Surgeon General [21] noted decades of research demonstrating efficacy of ABA to help children with ASDs increase communication, learning and social skills while decreasing misbehavior. There are now meta-analyses studies on EIBI effectiveness for autism for increasing functional adaptive skills, which translates into improved IQ score, decreased core symptoms of autism and improved participation in regular education, as will now be reviewed. Eldevik et al. [22] reviewed 34 studies looking at intensive ABA therapy for ASD based on the Lovaas UCLA Young Autism Project. The authors found a large increase in IQ and improved symptoms after EIBI. The results suggested that a formal Lovaas approach works better than a mixture of eclectic strategies typical of many autism special education preschools. Another systematic review of evidence-based practices for ASDs, the National Standards Project [23], brought a multidisciplinary, national expert panel together to review scientific studies on autism interventions. All published behavioral and educational interventions from 1957-2007 for persons with ASD between the ages of 0 to 21 years were reviewed (755 scientific articles). The results contributed to the California Department of Developmental Services ASD practice guidelines [24] and were highly supportive of published EIBI-ABA interventions.

Evidence of ABA effectiveness for ASD dates back to 1960s research showing decreased self-injury, increased verbal imitation and communication and improved play, self-help and academic skills in children with autism [25-28]. Lovaas et al. [29] summarized critical findings. Younger children benefited more. High intensity intervention yielded greater developmental gains than low-intensity services. However, early studies suggested the gains did not generalize across settings or skills. Landmark research was then published by Lovaas [30] on intensive intervention for young children with autism incorporating teaching across all significant developmental areas and environments to promote generalization. Children in the experimental group received 40 hours of ABA-EIBI for a 2 to 3 year period. Comparison control groups included a group that did not receive ABA, while another group received low intensity ABA (10 hours per week or less) over that same time period. Results showed that nearly half of the 19 children in the experimental group but almost none of the children in the matched control groups were able to participate in regular schooling. Intelligence Quotient (IQ) scores were significantly improved in the experimental versus control groups, as mean pre-treatment IQ for all groups was 60 but only the experimental group showed a clinically significant improvement in post-treatment IQ (mean IQ-83). Other studies confirmed findings of significant developmental gains from intensive intervention [17,31-36]. Sheinkopf and Siegel [32] showed pre-and post-treatment IQ gains from 63 to 90 in a treatment group of children who received 15 months of ABA-EIBI services for 27 hours per week in comparison to a simultaneous control group that received no ABA and showed minimal IQ gains. Howard et al. [17] showed pre-versus post-treatment IQ gains from 58 up to 90 in an experimental group of children with autism who received 14 months of ABA-EIBI for 30-40 hours per week, compared to minimal IQ changes in two control groups (one control group received 14 months of ecletic preschool education for 30-40 hours per week while the other group received 14 months of low-intensity special education for 15 hours per week). Thus, specialized ABA-EIBI programs gave superior results over preschool intensive education. Sallows and Graupner [33] studied 24 children with autism randomly assigned to a treatment group that replicated the EIBI Lovaas program or to a parent-directed group that received intensive hours but less supervision by equally well-trained ABA supervisors. After four years of treatment, outcomes were similar for both groups with clinically significant improvements in cognition, language, academics, social and adaptive skills. Fully 48% of children showed a “rapid learning profile”, achieved average post-treatment scores, and, at age 7, were succeeding in regular classes. Results were consistent with findings of Lovaas [30] and McEachin et al. [36].

Critical Analyses of EIBI Research

Some highly publicized reports suggest the evidence for EIBI remains insufficient and the research field suffers from methodologic concerns [37,38]. Subgroups of children with ASD are documented to show more moderated treatment response for unclear reasons. However, one report [37] acknowledged that the combined Lovaas-based and ESDM research suggests benefit from early intensive approaches for some children that should continue to be studied. Overall, the majority of systematic reviews do regard the evidence as strong [38]. Although some insurance carriers have questioned the strength of evidence [39], others have accepted it. Behavioral treatment is now mandated by law in many states. Ethically and legally then, it is important that children with ASD be offered reasonable intervention based on the state of science to date.

Common Misconceptions about ABA-EIBI

Misconceptions abound about ABA behavioral interventions for ASD, even among health professionals. A notion frequently espoused is that a skill learned through ABA will not generalize to daily life. In reality, the field of ABA has published extensive research defining the concept of, and delineating procedures to promote generalization [40]. Lovaas [30] showed that training across skills and settings promoted generalization of gains, resulting in treated children being able to attend regular education classes. Another misconception is that children with low IQ will not respond to ABA-EIBI. In fact, multiple studies have shown that initial IQ within the moderate to mild range of intellectual disability does not predict responsiveness to EIBI [41]. Claims are
made that ABA treatment makes children with ASD “robotic”, yet the successful integration of these children into regular classrooms after EIBI argues against production of “robotic” responses. Quality EIBI programs promote reinforcement for all socially significant skills in the natural environment.

Critical Issues affecting EIBI Access for Children with ASD

Key issues affecting access to EIBI include informed consent, obtaining reliable funding sources, the concept of “medical necessity” and monitoring results for continued authorization of services.

Informed consent is a legal and ethical obligation that involves communication between a patient (or the family for a child) and the health professional about choices and nature of treatment for a condition. In the communication process, the treating professional providing said treatment should discuss the diagnosis, nature and purpose of the proposed treatment with risks and benefits, alternatives (regardless of cost or the extent to which treatment options are covered by health insurance) and the risks and benefits of alternative treatment versus not treating. The family should have an opportunity to ask questions about treatment in order to make an informed decision to proceed or refuse a particular treatment course. The communication process must be documented, to ensure an appropriate discussion. The advent of laws requiring health insurance coverage of behavioral intervention for ASDs, including ABA services, creates new legal and ethical obligations for health professionals that authorize and fund such behavioral interventions. A physician cannot provide informed consent about treatment options to the family of a child with ASD unless they themselves are informed about such options. These professionals need to be adequately informed on the efficacy of ABA-EIBI treatment and the ABA treatment options for ASDs in their communities. The professionals need to share sufficient, accurate information in order for families to make informed decisions. Health professionals need training on what constitutes a quality ABA-EIBI program and health care agencies should conduct monitoring of treatment quality, the child’s progress, how challenges in progress are problem-solved and have evidence-based exit criteria from treatment. Given the extent and complexity of scientific literature on ABA treatment of ASDs, health professionals involved in informed consent and authorization processes who are not specifically ABA-trained should seek input from professionals who are so trained. Legislation mandating health plan coverage of behavioral services for ASDs is ahead of the general knowledge of many medical professionals about these behavioral services, and the information gap needs to be corrected.

Some medical professionals argue that EIBI is educational and not necessary medically, but this is not holding up legally, since legislation in many states mandates health insurance coverage of ABA services for autism [42]. The distinction between educational and medically necessary services is arbitrary, with overlap. Additionally, educational programs are often not equipped to deal with intense remediation needs of children with ASDs nor do they necessarily have school personnel adequately trained in highly specialized EIBI services. Further support of this is provided by research showing superior results of specialized ABA-EIBI versus eclectic preschool programs [17].

There is precedent for collaboration between health agencies and educational systems to meet exceptional needs of disabled or ill children. An example includes hospital school programs, which help children regain academic progress during periods of hospitalization or (importantly for ASD) during rehabilitation. EIBI programs are habilitative/rehabilitative programs designed to capture developmental potential of children with ASD (or recapture potential, as fully one-third of children with ASD present with regression [43-45]). Hospital schools thus set a precedent of educational services that are medically necessary. They are typically run by the public school system and funded by the state, but receive collaborative medical support by being located on the hospital site in order to meet the extraordinary needs of the child. Relatedly, a young child with ASD presents extraordinary rehabilitation needs that call for collaboration between health care and educational systems in order to remediate multiple developmental deficits that will only grow over time without such rehabilitation.

Historically, the legal doctrine of medical necessity, which reviews whether services are necessary, reasonable and constitute evidence-based clinical standards of care, has been used by health agencies to deny access of children with ASD to EIBI. Yet services may be necessary for a variety of purposes, such as diagnosis or treatment of medical disorders to improve functioning. The ASDs are neuro-psychiatric developmental disabilities (hence, medical disorders) where substantial evidence shows that many of the behavioral symptoms that define ASDs are remediable to varying degrees when evidence-based practices such as EIBI are used. This argues for the medical necessity of EIBI, not against it.

Considered mental health parity, there are a number of child psychiatric conditions that may require intensive outpatient or home-based services, such as intensive day-treatment programs [46]. Cognitive Behavioral Therapy (CBT), for example, is typically a covered health benefit for childhood psychiatric conditions including anxiety and mood disorders, and may be intensive for severe conditions. Children with ASDs are covered by mental health parity law for intensive behavioral services as for any other psychiatric disorder; hence EIBI comes under the umbrella of mental health parity.

To achieve quality outcomes, EIBI professionals require extensive and specific training, experience and credentials. The Behavior Analysis Certification Board (BACB) was formed in 1998 to meet credentialing needs of stakeholders [47] and has authority to withdraw credentialing for ethical or competency violations. The BACB has published guidelines for responsible conduct stating that certified behavior analysts (BCBAs and BCABAs) must use interventions that have proved effective in scientific studies. With the increasing demand for autism treatment, the ranks of behavior analysts have been growing. The increasing demand for services makes the need for monitoring the quality of autism-specific training of behavior analysts all the more critical. The rapid growth of EIBI companies creates great challenges for monitoring quality. Unfortunately, this can lead to delivery of sub-optimal EIBI. Apart from the efforts of the relatively small BACB board, there is little regulation of EIBI. Typically, funding agencies are unequipped to assess EIBI providers [48]. There are relatively few academic training resources for EIBI providers [47], with thousands of new ABA companies across the country. Funding sources are trying to rein in costs. The solution resides, in part, on health insurers networking with ABA professionals who have extensive autism-specific experience and a substantial track record for quality outcomes.

Monitoring EIBI Results

A difficulty for regular monitoring of a child’s developmental progress in early intervention is that there is no standardized, normed developmental tool that should typically be used more often than every 6 to 12 months. Additionally, measuring progress in a curriculum (as is done in the HELP, VB-MAPP and the Early Start Denver Model
Curriculum Checklist) is a different sort of measurement than a standardized assessment of the child’s skill level compared to normative performance of same-age peers. An issue is that no test has yet been developed specifically for the purpose of measuring progress in EIBI, in which program decisions need to be made day by day and week by week, not just on a semi-annual basis. Instruments initially designed for other purposes in developmental assessment are therefore turned to in order to meet the monitoring requirements of health plans or other agencies for a child receiving EIBI. Table 1 lists a number of the most commonly used instruments.

How to best assess a child’s progress in EIBI and which instruments to use (even potentially the development of new instruments) are important areas for future research. A funding agency review of the child’s progress in EIBI every 6 months is a common practice, supported by legislation in various states [63]. Health professionals making authorization decisions for initiating and continuing EIBI should be adequately trained to interpret progress data. Demonstrations of improved functioning with decreased problem behaviors and acquisition of functional communication as well as socially valid adaptive skills is supportive of continued EIBI. Optimally, professionals who initiate and reauthorize EIBI should have adequate training and experience to make those judgments, be objective, base decisions on the child’s developmental treatment data and be free from philosophical bias against ABA. There should not be disproportionate financial incentives to rein in costs that will hamper objectivity.

More research is needed on variables that reliably predict responsiveness to EIBI [64] to gain a better understanding of how to match children with ASDs with various evidence-based treatments in order to help consumers make better intervention choices [65-67]. Some guidelines to promote objective and evidence-based decisions on initiating and reauthorizing EIBI include:

1. Advocating only one specific type of treatment for children with ASDs, given the tremendous variability that children with ASDs show, is not supported by current evidence. Many researchers warn against a “one size fits all” approach, recognizing the need for individualization of ASD treatment [64-66]. Judicious changes in evidence-based protocols can turn a child with ASD who is seemingly a non-responder to behavioral treatment to a responder [67].

2. Initial cognitive and adaptive test results are not a reliable indicator of responsiveness to EIBI. Sherer and Schreibman and Sherer [64] found that responders to treatment often were either initially untestable or had very low scores on their first cognitive and adaptive measurements at about the same degree as compared to a group of non-responders.

3. Rate of developmental progress in the first 6 months of EIBI is a better indicator of treatment responsiveness rather than initial scores. Moderate to severe cognitive impairment in a newly diagnosed child with ASD is not a contraindication for EIBI. Initial cognitive test results may well underestimate the child’s learning potential. The child may not be motivated to perform on testing and may be difficult to test until they have been taught learning readiness skills.

4. Targeted ABA services for remediating serious problem behavior is effective, even in children with severe cognitive impairment. The presence of problem behaviors per se is not a contraindication to initiating or continuing EIBI.

5. While initiating treatment at the earliest age possible contributes to improved outcome, benefits can still be gained when intensive behavioral treatment is initiated at age 4 years or older [68].

6. There is no scientific literature to support 15 hours per week or less of EIBI programming. Indeed, a number of studies give evidence that greater than 15 hours per week of intervention is needed [17,19].

Given the pitfalls that can occur with EIBI, it is our opinion that families should be given choices about ABA providers from their health care provider. References of ABA-EIBI agencies should be checked from multiple sources. Some agencies may come highly recommended for reasons other than quality of service. Families may be discouraged from using agencies for reasons other than quality of service. If this occurs, legal and ethical obligations of informed consent are likely not met. It behooves the family and health provider to know the scientific literature on ABA-EIBI. There is danger of funding agencies pursuing the lowest common denominator of service that is legally defensible rather than a comprehensive evidence-based service. Unfortunately, there are ABA agencies that will cater to that. In the experience of the authors, personal biases against the science of ABA are not uncommon in the medical field and generally stem from a lack of awareness of how rigorous ABA is as a science.

Despite new health insurance coverage laws for behavioral services,
funding is still an issue. Often, there is split-funding between agencies (health care agency, school district and/or developmental regional centers may share funding responsibilities). Levels of service may vary based on the funding source, rather than on what is evidence-based and needed by the child, which further constitutes a threat to quality ABA intervention.

One cost-benefit analysis [69] showed the cost of not providing ABA-EIBI for children with ASDs becomes much greater than the cost of treatment. This analysis used a cost-benefit model with representative costs from the state of Pennsylvania, assuming the child with ASD had average participation in EIBI for 3 years between the age of 2 and school entry. A variable range of outcomes from EIBI was assumed, with some children ultimately participating in partial special education, others in intensive special education, and some in regular education without supports. The model estimated societal cost savings ranging from $187,000 to $203,000 per child for ages 3-22 years and from $656,000 to $1,082,000 per child for ages 3-55 years in constant dollars.

Bringing Treatment into the Medical Home
A patient-centered medical home denotes a health care setting that facilitates partnerships between medical providers, the individual and the family [70] to improve health outcome and quality of life. Golnik et al. [71] noted that while primary care providers are called on to provide comprehensive medical home care, they report a lack of self-perceived competency but a desire for education and a need for improvement in primary care for children with ASD. Important tools have been developed to address these issues, including the AAP autism toolkit, the National Medical Home Autism Initiative at the Waisman Center, the AAP National Center for Medical Home Implementation Autism Information and CDC training curricula. Yet even these tools are limited in addressing the complexities of EIBI that have evolved over more than three decades of intensive psychological research stemming from pioneering work of many distinguished psychologists. These pioneers include but are not limited to Dr. Ivar Lovaas, Dr. Gina Green, Dr. Robert Koegel, Dr. Sally Rogers, Dr. Geraldine Dawson (all already cited in this article) and many others. Given that the primary treatment advances in ASD at this time are psychological and behavioral, it is important to integrate psychological and behavioral knowledge into the medical fields to achieve multidisciplinary and translational benefits, out of the research institutions and into primary medical care in the community. More needs to be done to enable physicians to make good clinical decisions with regard to EIBI for autism.

Limitations of this Article
In the interest of brevity, the fundamental purpose of this article is ultimately not to compare known behavioral and educational treatments of children with ASD. Instead, the purpose is to promote the state of EIBI evidence as one specific approach for ASD that the authors believe will improve medical care of children with ASD. Myths need to be dispelled regarding EIBI, which is best done by examining the scientific evidence existent to date. Evidence has been presented that behavioral treatment for ASD makes the most impact when it is started early, is of high quality with adequately trained and supervised staff, gives a sufficient intensity-level of services (25-40 hours a week) and adheres to evidence-based strategies published in the scientific literature. Low cognitive and adaptive performance on initial assessment does not reliably predict treatment responsiveness, so toddlers with low initial scores should not be denied access to EIBI. Similarly, behavioral problems are not a contraindication for offering EIBI, since such behavioral intervention has evidence-based strategies to address behavioral problems. Funding agencies should monitor progress in EIBI at least every 6 months. Before terminating EIBI services based on lack of progress, the quality of services should be assessed and any needed quality improvements should be implemented first. Health providers must increase their knowledge of evidence-based autism intervention and obtain input from highly trained ABA specialists with direct, extensive experience treating autism if improved developmental outcomes within the medical home and long-term societal savings, shown to be significant in a cited cost-benefit analysis, are to be achieved.

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