STRAIGHT TALK About Autism

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Treatment Options and Parent Choice
Is ABA the Only Way?

As noted in part one of this three-part series, educational and treatment approaches for children with ASD tend to be limited with respect to family-centered practice, and there is a dire need to move practice in this direction. In this discussion, we will consider a very popular and influential category of treatment approaches—*applied behavior analysis*—given that it is illustrative of an intervention technique that is often promoted in a manner that violates principles of family-centered philosophy and practice. More specifically, a subgroup of professionals in applied behavior analysis (ABA) has espoused an "ABA only" approach for children with ASD, and makes recommendations conveying this restrictive message to families and agencies serving children. Claims that "our approach works and others do not" is heard primarily from some leading proponents of ABA, and rarely if ever heard from proponents of other available treatment and educational approaches, or from independent sources. I regularly speak to many experienced professionals and parents who have become increasingly concerned about these statements, since they convey inaccurate information to families that is not supported by current research and practice. When this occurs it can result in confusion for families and mistrust of professionals, thereby undermining the critically important parent–professional partnership. Furthermore, it can also result in limited treatment options for parents to consider, as parents are often told that they have no need to look further, and no need to educate themselves about the range of approaches available. In my consulting practice, I hear repeatedly from parents of older children that in the early years they were led to believe that ABA was the only credible approach that was available, and that they wish they had been exposed to, and educated about the broader range of intervention practices for children with ASD.

Before examining some of the claims made for ABA, a few brief comments are in order, since ABA is often discussed as one specific, definitive approach or treatment, which is not accurate.

1. **Definitions of ABA vary greatly, as do practices that fall under the heading of ABA.** Dr. Laura Schreibman, a highly respected contemporary ABA researcher and practitioner, recently stated that "Technically, applied behavioral analysis is not a treatment for autism, it is a research methodology" (Schreibman, 2007). This view is in stark contrast to that espoused by many parents and professionals in which the term ABA is used synonymously with discrete trial training, within the context of a program consisting primarily of highly regimented, adult-directed one-to-one instruction. Recommendations or prescriptions—such as "Johnny needs 40 hours of one-to-one ABA"—is but one example of such confusion. The range of application of the term ABA, especially when used by ABA practitioners or those prescribing ABA services, makes it difficult to discern what is meant when reference is made to ABA as a treatment approach.

2. **The range of practices under the heading of ABA has evolved over the past 30 years and now varies from traditional practices to contemporary practices.** (Prizant & Wetherby, 1998; 2005)

   Traditional ABA practice is characterized by highly structured, adult-directed teaching referred to as discrete trial instruction or training (DTI or DTT, respectively) that focuses on teaching correct responses in regimented, prescriptive teaching formats. Most often, such practice is determined by programs that must be followed faithfully when "training" skills. Major objectives include maintaining "instructional control" and "compliance" while teaching

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and eliciting correct responses that are targeted in teaching programs. Traditional ABA practice uses primarily adult-child (one-to-one) teaching formats to the exclusion of social instruction in various social settings, and typically does not focus on the core social-communicative and relationship challenges faced by children with ASD.

Contemporary ABA practice is characterized by more flexible, naturalistic teaching (e.g., incidental teaching) in natural routines and activities that focus on social initiation and spontaneity. Based on the significant limitations of traditional ABA practice, many ABA practitioners have moved away from highly structured and regimented practice to practices that have a much greater focus on social communication across a variety of social settings. In many ways, contemporary ABA practice, such as incidental teaching and pivotal response training, is more similar to developmentally-based approaches (e.g., DIR, RDI, SCERTS) than it is to DTT.

Over the past two decades, the clear trend within ABA practice has been movement from traditional to more contemporary practices, as research has not supported the effectiveness of traditional ABA practices in teaching social communication and other critical, functional skills. (Koegel & Koegel, 1995, 2006; Strain, McGee, & Kohler, 2001).

3. **Contemporary ABA researchers have criticized ABA approaches that use DTT and other adult-directed teaching as the predominant instructional method, citing its limited effectiveness.** Their concerns include: 1) the use of teaching strategies that do not foster social communication, communicative initiation, or the formation of relationships, all of which are core challenges in autism; 2) a teaching format that is primarily adult-controlled and that discourages initiation and spontaneity in communication and learning by placing a child in a respondent role, resulting in passivity and prompt dependence; and 3) the teaching of skills that may not be appropriate to a child's developmental level or functional needs, and that remain limited to the teaching situation; that is, they do not meaningfully generalize to independent use in daily interactions and activities. In fact, due to these concerns, several of the most well-respected and highly published researchers in ABA and ASD over the past three decades—including Drs. Robert and Lynn Koegel, Laura Schreibman, Phil Strain, and Gail McGee—have been openly critical of traditional ABA practices, and have abandoned such practices in favor of more naturalistic approaches that have a strong developmental and child-centered basis (Koegel & Koegel, 1995, Strain, McGee, & Kohler, 2001, Schreibman, 2007).

Claims Used to Support Traditional ABA Practices that Limit Family Options and Choice

The following are examples of claims about ABA that are still made frequently, despite the fact that they are not supported by research:

Claim # 1. Research has concluded that ABA is the *only* effective or *most* effective approach for children with ASD, and therefore is the "gold standard" of treatment.

Not supported—The most comprehensive review of educational research to date, conducted by the National Research Council (a committee appointed by the National Academy of Sciences, NRC, 2001), concluded that given the current state of research in ASD, there is no evidence that any one approach is better than any other approach for children 0-8 years of age. The report noted, "Studies have reported substantial changes in large numbers of children receiving a variety of intervention approaches, ranging from behavioral to developmental." (NRC, 2001)

Claim # 2. Once a child is diagnosed with ASD, he or she must receive ___ hours (25, 30, or 40 hours) of ABA services—often recommended to be delivered in a DTT format—in order to make progress.

Not supported—Following a comprehensive review of research, the National Research Council recommended that children with ASD need active engagement in intervention for least 25 hours a week. *It did not, however, specify any particular treatment approach*, and as noted, there is research evidence that documents substantial positive changes using a variety of intervention approaches, from behavioral to developmental. Furthermore, the NRC noted that the most important areas of focus must include:

a) Functional, spontaneous communication

b) Social instruction in various settings (not primarily 1:1 training)

c) Teaching of play skills focusing on appropriate use of toys and play with peers

d) Instruction leading to generalization and maintenance of cognitive goals in natural contexts

e) Positive approaches to address problem behaviors

f) Functional academic skills when appropriate

ABA approaches vary greatly regarding the extent to which they focus on these practices, with contemporary ABA approaches more consistent with these priorities.

Claim # 3. A child with ASD will benefit the most from ABA services that use a DTT (discrete trial teaching / training) format, because:

a) Certain readiness skills must be acquired before a child can benefit from social learning experiences (the readiness "myth")

b) Children with ASD (especially young children) can only learn in 1:1 teaching formats, and cannot learn from other children (the tutorial 1:1 instruction "myth")

c) Typical environments are too over-stimulating for a child with ASD to learn in (the over-stimulation "myth")

d) Behavior cannot be controlled in more typical settings (the behavioral control "myth")

Not supported—Three well-published and highly-respected applied behavior analysts in ASD, Drs. Phil Strain, Gail McGee, and Frank Kohler, devoted an entire chapter to these claims, and reviewed research to see if there was any support for them. They concluded, "These myths rest on shaky, if not absent empirical grounds." (from Strain, McGee & Kohler, 2001)

Claim # 4. If a child does not receive intensive ABA by five years of age, the "window of opportunity" for learning will close, or it will be missed.

Not supported—There is no evidence that there is a ceiling on learning, or that there is a window of opportunity that closes. When the idea of a "window of opportunity closing by a certain age" is conveyed to parents, it may cause significant stress and even guilt for those families who started services later (causing them to feel that they have missed their "golden opportunity"). This may happen when children are diagnosed beyond three years of age; in situations when families do not have access to services; or when a child is unable to fully participate in available services due to issues beyond the control of the family (e.g., illness in the family; living in poverty or in rural settings; or when diagnosis is deferred by professionals).

It is important to note that the "window of opportunity" statement is an inaccurate rendering of a statement that is true:

There is no evidence that there is a ceiling on learning, or that there is a window of opportunity that closes.

One of the factors associated with better outcomes is early entry into intervention.

This, however, is only one of a number of factors that is associated with children doing better. Others involve inclusion of a family component and active family involvement in programming; developmentally appropriate activities; 25 hours of engagement in individualized programming per week; and exposure to repeated, planned teaching opportunities (NRC, 2001). Based on my experience, and the experience of colleagues and families I have known over three decades, it is clear that learning and developmental progress for children and older individuals with ASD is life-long, just as it is for all human beings. In many cases, I (and others) have observed significant and sometimes dramatic progress well beyond the preschool years and continuing into adulthood.

Claim # 5. ABA is the only educational approach that results in "recovery" from autism, which occurs in about half of the cases.

Not supported—When this claim is made, the studies that are most frequently cited are those of Dr. Lovaas and colleagues (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993), in which 19 children receiving intensive ABA services were followed, and 9 were considered to have "recovered" (i.e., considered to be "indistinguishable from peers") at follow-up. However, there are a number of problems with this claim.

1. First and foremost, these studies have been severely criticized for the claims made given the very small number of subjects, the type and intensity of treatment provided, and the absence of treatment fidelity measures (see, for example, Gresham & MacMillan, 1997, 1998, and Prizant & Rubin, 1999). *To date, approximately 20 years following publication of the first Lovaas study, there has been no successful replication of the original results, with a number of failed attempts.*

2. The issue of "recovery" from autism, and even the definition of the term *recovery* (i.e., the state of being indistinguishable from typical peers) remains controversial, and the likelihood of recovery for a significant proportion of children has not been supported in long-term follow-up studies of children who received a variety of interventions. Clearly, many children do go on to make significant progress, doing well academically, developing social relationships, and having a positive "quality of life", even if they continue to qualify

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for a diagnosis, and continue to experience some of the challenges associated with ASD. (For more discussion on this complex and controversial topic, see my article, *On Recovery*, in the summer, 2008 issue of *ASQ*.)

Claim # 6. There are hundreds of studies that demonstrate that ABA works, and few or no studies that demonstrate that other approaches work.

Not supported—There are a considerable number of studies conducted by ABA researchers that demonstrate the effectiveness of *specific* elements of practice, many of which were initially developed outside of the field of ABA, but were eventually adopted by ABA practitioners. Examples include teaching verbal communicative skills and communicative replacements for problem behaviors; social skills; visual communication systems; visual schedules; play and recreation skills; community living skills; and relaxation and other emotional regulatory strategies. However, there are very few studies that have looked at the effectiveness of *comprehensive* intervention programs; that is, those that simultaneously address a variety of domains of learning and skill development for a child and family over time. This is true for ABA as well as for other intervention approaches (NRC, 2001). Furthermore, virtually all of the research cited to support the efficacy of ABA—especially research resulting in claims that ABA is the best or only approach that works—is conducted by proponents and practitioners of ABA. Carl Dunst, one of the most respected voices in family-centered and evidence-based research in the field of childhood disabilities, recently stated "it is important to discern which practices are and are not efficacious without a preconceived bias or presumption of effectiveness for one practice over another" (Dunst, 2009). Thus, this basic tenet of objectivity in research is consistently violated in ASD efficacy research, both for ABA as well as for other approaches, as most studies are typically conducted and published by proponents of the specific approach under investigation.

Summary and Conclusion

In the December, 2008 issue of the *Autism Advocate* devoted to the topic of ABA, the editors noted that "Increasingly, researchers have been suggesting that the idea that there is a *best* treatment for autism is counterproductive and misleading" (Carr and Granpeeshah, 2008). I wholeheartedly agree with this statement. The individual differences observed in both children and their families call into question the notion that any one approach—or even one category of approaches can meet the needs of all children and families. Yet, it is ironic that the "best treatment" claim is stated most frequently by some proponents of ABA, and rarely, if at all, by proponents of other approaches. When the message "ABA is the only way" is conveyed in print, at conferences, and in educational/treatment programs, especially to parents of young children, it violates the primary goal of family-centered practice, which is to support parents in making the most informed decisions for their child and family through increasing knowledge and understanding of the variety of treatment options available. To be clear, principles and practices in applied behavior analysis have long made contributions to intervention and educational programming for children with ASD; however, the notion that it is not possible to have quality programs unless they are ABA programs is not supported by current research and practice. Specifically, there is no credible research that supports these claims, and there is a great deal of emerging evidence to the contrary. Furthermore, when such claims are used to steer families *exclusively* toward ABA practice, and away from other considerations, it is a disservice to children with ASD and their families when the result is limitations in parent input and choice about treatment options.

I will conclude with a quote from the late Bernard Rimland, Ph.D., a parent of an individual with autism; a recognized pioneer in the field of autism; and a tireless parent advocate, and long-time supporter of ABA practice:

"The "ABA is the only way" folks are wrong, not only because of their lack of information about research on the validity of other interventions, but because of their failure to recognize that parents have a right and an obligation to consider all possible forms of intervention, including those which may not yet have won the stamp of approval of whatever person or committee feels qualified to pass judgment on candidate interventions."

In part three of this three-part series I will address specific steps that practitioners and parents can take to infuse family-centered principles and practices into the educational and treatment approaches they choose for their children.

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Bio

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