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*Corresponding author: Aileen Herlinda Sandoval-Norton, Clinical Services, Alternative Teaching Strategy Center, United States
E-mail: aherlindasandoval@gmail.com

Reviewing editor:
Jacqueline Ann Rushby, Psychology,
University of New South Wales,
Australia

Additional information is available at
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How much compliance is too much compliance: Is long-term ABA therapy abuse?

Aileen Herlinda Sandoval-Norton^{1*} and Gary Shkedy²

Abstract: This article discusses the prevalence of ASD with specific regard to the most ubiquitous current treatment, Applied Behavior Analysis (ABA). A discussion of some of the issues with the underlying theory of ABA in its current application is conducted, especially with regard to “lower functioning” and nonverbal autistic individuals; namely, the curtailing of soothing “stimming” behaviors, operant conditioning, behaviorist principles that research has continued to prove it is not apt for usage with autistic individuals, as well as the unintended but damaging consequences, such as prompt dependency, psychological abuse and compliance that tend to pose high costs on former ABA students as they move into adulthood. Serious issues with the application of ABA to autistic students, specifically “lower functioning” and nonverbal ones, are discussed, especially with regard to lack of current and longitudinal scientific testing and research with respect to these individuals. These effects and the trauma that occurs resultantly are categorized as abuse. Finally, drivers of the expanded usage of ABA within the autistic community despite a lack of efficacy are also discussed, such as a potential current market size as large as \$17 billion annually and the deficiency of variety in techniques used by the psychologists and behavior technicians who utilize ABA with ASD students, as well as a lack of introspection about the true effectiveness of the technique amongst the whole population on the part of these professionals.

ABOUT THE AUTHOR

Alternative Teaching Strategy Center (ATSC) is a non-profit organization located in San Diego, California dedicated to providing services to families with children and adults with autism and other cognitive and learning disabilities. ATSC works directly with parents, insurance companies, school districts, and other State agencies, and provides one-on-one treatment services to children and adults from all over the world. ATSC is dedicated to researching treatments and interventions primarily in autism and related disorders with a primary focus on severe autism, due to a sparsely populated research base. The group's work includes topics related to the effective overall treatment options and methods, the use of technology in treatment, implementation of special education especially in public schools, socialization, and ethical practice, with a goal of improving the quality of life for the aforementioned populations

PUBLIC INTEREST STATEMENT

The rate of Autism Spectrum Disorder (ASD) has been increasing each year, it currently affects 1 in 59. Additionally, 35-50% of these children will remain minimally verbal or non-verbal. However, while the rates of ASD have been increasing, our treatment options have not. The aim of the current paper is to call attention to outdated approaches to treating Autism, especially for the nonverbal children. The current treatment options for these children not only goes against current knowledge and research on ASD, but while unintended, creates lasting damage and abuse which also goes against the very oath professionals take to do no harm. The current paper hopes to stimulate conversation on this important topic so that parents, professionals and paraprofessionals can begin to advocate for this vulnerable population and protect them from further abuse.

Subjects: Cognitive Psychology; Counseling Psychology; Developmental Psychology

Keywords: abuse; trauma; therapy; Autism; applied behavioral analysis; conditioning; compliance; child; adolescent; Autism treatment; nonverbal

According to the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Autism Spectrum Disorder (ASD) is identified by a unique set of deficits including social communication and interaction, and restricted or repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). Per the DSM-5, ASD affects approximately one percent of the population, with at least 15% of cases associated with an established genetic mutation (American Psychiatric Association, 2013). However, both prevalence rates and heritability estimates vary across studies. In fact, twin studies estimate phenotype variance due to genetic factors to be as high as 90%. (Tick, Bolton, Happé, Rutter, & Rijdsdijk, 2016). Additionally, in their most recent biennial update, the Centers for Disease Control (CDC) indicated a 15% increase in prevalence nationally to 1 in 59 children, from 1 in 69 two years prior (Baio et al., 2018). In the same report, the CDC indicates that about 31% of children with ASD were classified as intellectually disabled. In addition, approximately 25–50% of children with ASD do not develop functional verbal communication (Pattern, Ausderau, Watson, & Baranek, 2013). It is this subset of nonverbal children who are classified as intellectually disabled that are the most vulnerable of all the children with ASD.

Autism's relevance and prevalence is slowly creeping to the forefront of modern day medicine and cultural awareness. While one could argue that resources, media, research, and education allocated to ASD is late and lacking, it is important to acknowledge that ASD is not an individual's disorder. ASD affects more than the individual patient—it can affect family systems, communities, school systems, healthcare systems, economic projections, and more. Unfortunately, while prevalence rates are changing and increasing, our treatment options are not. This is likely due to the popularity and misconceptions surrounding Applied Behavior Analysis (ABA), which has been largely accepted as the gold standard for the treatment of Autism Spectrum Disorder (Vismara & Rogers, 2010).

Applied Behavior Analysis is a form of behavior modification that relies heavily on external reinforcement, both positive and negative (operant conditioning). ABA is intended to modify or diminish behaviors, as well as increase language, communication, social skills, attention, etc., in children with ASD. The main tenets of ABA follow behaviorist theories that suggest that behavior is caused by external stimuli in the environment, which is why a reward (external) would reinforce a behavior, and punishment (external) would discourage a behavior. While operant conditioning may be effective for teaching specific tasks in certain situations, in nearly all other circumstances it is not typically used to the extreme extent that it has been applied with for the treatment of many children with ASD. Take toilet training for example; many typical children and children with ASD are toilet trained using operant conditioning. However, this conditioning only applies to the one skill—and once they have mastered it, the conditioning subsides. Conversely, many children with ASD are taught the same task or skill for years using the same conditioning techniques yet mastery is never met. ABA therapy has been viewed as the gold standard for treating children with ASD because various meta-analyses have found it to be very efficacious (Eldevik et al., 2009; New York State Department of Health Intervention Program, 1999; Virués-Ortega, 2010). However, research indicates efficacy only with those who have a measurable Intelligence Quotient (IQ), typically at 70 or above (Virués-Ortega, 2010). Many studies use IQ to measure efficacy or as an inclusion criterion, which means children who are nonverbal, particularly those deemed as “lower functioning” and untestable, are inherently excluded from these studies (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011). Therefore, nearly all research on ABA efficacy excludes the nonverbal population; yet, this is the population that tends to receive continual ABA services over a longer period of time since they often do not meet the criteria needed for mastery of tasks for months or even years.

Ivar Lovass (1996), the grandfather of behavioral treatment for Autism, when describing criteria for proposed behavioral treatments stated that it should only be used with auditory learners, as visual learners “do not recover with behavioral treatment” (p.2). There have been limited, if any, scientifically validated studies on the use of ABA on nonverbal children with ASD. Therefore, the most vulnerable children with ASD cannot be tested and as such should not be candidates for such behavioral treatments. Why then is such intensive conditioning utilized on a population that would never be included in the studies that advocate for the usage of such behavioral treatments? Moreover, despite having produced a generation of nonverbal children who have undergone many years of ABA therapy, often well into adulthood, there is limited research on the status of these individuals, most notably their propensity for independence and whether ABA therapy has on the whole helped or hurt these individuals.

Nonverbal children with ASD are exposed to operant conditioning in all aspects of their lives, until they are aged out at sometime between age 18 and 21 years when services are no longer required by law (Individuals With Disabilities Education Act, 2004). In fact, schools, ABA specialists, and researchers are learning that such intensive and chronic conditioning has instead amounted to compliance, low intrinsic motivation, and lack of independent functioning—the latter of which is the presumed goal of ABA therapy in the first place (Wilson, Beamish, Hay, & Attwood, 2014). Perhaps because ABA therapy is considered effective in verbal children and in typical children for select tasks, the assumption is that an even more intensive approach would be suitable for nonverbal and/or “lower functioning” children with ASD. Regardless, research has indicated numerous problems with the underlying theory of ABA, specifically unintended consequences such as prompt dependency, amongst other issues (Bryan & Gast, 2000; Mesibov, Shea, & Schopler, 2004). While conditioning and prompting is initially meant to facilitate learning and help accommodate challenges related to autonomous functioning, the usage of prompting often does not fade even when the need for it has. Prompting is used to compensate for challenges related to independent functioning, and was intended as a temporary aid (Hume, Loftin, & Lantz, 2009; Cooper, Heron, & Heward, 2007). However, research has consistently found that individuals respond to the prompts instead of to the cues that are expected to evoke a target behavior, ultimately contributing to learned helplessness and arguably to low self-esteem (MacDuff, Krantz, & McClannahan, 2001; Sternberg & Williams, 2010). This may also explain why intensive conditioning in nonverbal children rarely generalizes to other tasks, assuming the targeted task is even mastered.

Regrettably, the damage done by ABA therapy through this kind of intensive conditioning goes beyond adult reliance and learned helplessness. There is little evidence of prompts fading in order to decrease dependence and encourage students to respond to other people and more naturally occurring cues. In one particular study, dependence was even observed on playgrounds when a child could clearly engage in a task or play autonomously, but hesitated when a paraprofessional was near (Giangreco, Edelman, Luiselli, & MacFarland, 1997). The proximity, constant prompting, and intensive conditioning has produced various issues that proponents of ABA therapy, and child advocates in general, have failed to study. Research has indicated many problems with the premises behind ABA therapy and various similar interventions, yet longitudinal research examining the lives of the adults who have been subjected to such conditioning since childhood is few and far between (Mesibov et al., 2004; Sternberg & Williams, 2010; Wilson et al., 2014).

Research has also indicated the psychological impact of external reward systems and the impact of produced compliance (Gudjonsson & Sigurdsson, 2003; Lepper, Greene, & Nisbett, 1973). Detrimental effects are noted after the introduction of a reward such as reduced motivation, reduced intrinsic interest, and reduced performance quality in both typical and non-typical children. Additionally, the reward-expectation even lingers after changing the target task and the environment, indicating that the only thing that is being generalized is low motivation and the need for rewards (Deci, 1971; Deci, Koestner, & Ryan, 1999; Lepper et al., 1973; Wiechman & Gurland, 2009). One small study even found evidence of increased post-traumatic stress symptoms in those exposed to ABA (Kupferstein, 2018). Compliance can be referred to as “the tendency

of the individual to go along with propositions, requests, or instructions, for some immediate instrumental gain” (Gudjonsson, 1992, p. 137). While compliance has been known to lower self-esteem, it has also been strongly correlated with certain types of coping skills, most notably denial and behavior disengagement. (Carver, Scheier, & Weintraub, 1989; Graf, 1971; Gudjonsson, 1989; Gudjonsson & Sigurdsson, 2003). This results in either attempting to reject the reality of a stressful event, or withdrawing effort. In fact, these patterns of coping skills can even be seen in “high functioning” individuals who have engaged in ABA conditioning, and consequently follows them into adulthood. Spouses of individuals with then-called Asperger’s Syndrome who were exposed to conditioning utilized in ABA, disclosed living with the consequences of prompt dependency and identified lack of self-motivation as a constant source of stress within their relationships (Wilson et al., 2014). These spouses also identified as filling a parent or caregiver role instead of a partner role. Additionally, prompting was found to be embedded within most that couples’ interactions and generally permeated their relationship (Wilson et al., 2014). Other research indicates that prompt dependence has been found to inhibit or prevent the development of age-appropriate social relationships and interpersonal skills in children, which also contributes to lack of motivation and unsuccessful learning (Malmgren & Causton-Theoharis, 2006). Considering research previously noted, it is not surprising that ABA therapy has long-term consequences, and has created prompt-dependent adults who lack in self-motivation and self-esteem. Shockingly, there is a lack of research that describes the many years of relentless conditioning of nonverbal children who cannot defend or express themselves. These children are forced to endure this kind of conditioning until a therapist or school district decides the child is incapable of learning, and abandons all attempts at teaching—but where are these adults now? What have they learned? Where is the longitudinal research that supports the continued use of such extreme conditioning in nonverbal children with ASD? And why are the negative impacts of such intense conditioning being ignored?

A lifetime of punishment and reward without an understanding of the task that is being asked, can create individuals who are compliant and conditioned to obey others, independent of a task. It creates individuals without intrinsic motivation, self-confidence, or self-esteem to successfully engage in any task. A lifetime of having food, candy, toys, and other objects being withheld without an understanding as to why, can create learned helplessness, anxiety, and stress. Various punishments such as misting the child in the face with water, taking away desired objects, withholding attention from the child, ignoring the child, or removing the child from the situation, and even electric shock have all been utilized without hesitation or contemplation of the long term psychological consequences (Carr, 1977; Minshawi et al., 2014; Weiss, 2003). A lifetime of prompt dependence can create adult-reliant children, and robs them of the opportunity and potential for learning and growth. Interventions that result in years spent trying to force a child to engage in eye contact, condition a child to stop stimming or obey commands such as “hands down,” with no apparent understanding of the function of such behaviors for children with ASD, is undoubtedly abusive and frankly irresponsible when understanding the autistic brain. Research indicates hyperactivity in various areas of the autistic brain which results in overstimulation and can explain a number of symptoms, such as aversive responses to eye-gaze (Dichter, Felder, & Bodfish, 2009; Martineau, Andersson, Barthélémy, Cottier, & Destrieux, 2010; Markram & Markram, 2010). This overstimulation is seen in the over-activation of the amygdala when eye-gaze is held for longer (Dalton et al., 2005; Markram & Markram, 2010). Research also describes the function of stimming in children with ASD similar to that of nail-biting, playing with hair, tapping one’s leg, etc., yet interventions have noted differences in stimming or movement and made arbitrary distinctions between which movements are pathological and which are not (Baron, Groden, & Groden, 2006). Additionally, many stimming movements or behaviors have been shown to be related to stress and anxiety, which can cause unusual sensations and movements to escalate, while others are related to painful sensory hyperactivity (Baron et al., 2006; Brenner, Friedman, & Merritt, 1947). A lifetime of being punished for certain movements, and being forced to engage in eye contact despite the physiological pain and discomfort of doing so, is psychological and physical abuse. A lifetime of being forced to sit still with no regard for actual cognitive abilities can create further emotional and psychological harm. With such drastic methods of conditioning, it is heartbreaking but not

surprising to learn that the odds of being a victim of a violent crime is doubled among individuals with disabilities, and individuals with cognitive disabilities have the highest risk of violent victimization (Harrell & Rand, 2010). Additionally, individuals with disabilities are sexually assaulted at nearly three times the rate of those without disabilities (Disabled World, 2012). So how much compliance is too much compliance?

As research continues to find negative impacts on children and adults who have been subjected to years of ABA interventions, psychologists need to ask themselves whether or not this archaic approach to treating ASD is in line with their oath to do no harm. Those immersed in the field of psychology, especially practicing clinicians, have known about and presently use interventions that are derived from a number of theoretical orientations and schools of thought in their everyday practice. To apply only behaviorist principles, to vulnerable children without voices, completely disregarding newer, better researched or more holistic interventions, especially at the extreme that ABA promotes, is frankly irresponsible, damaging, and goes against the code of ethics (American Psychological Association, 2010, 2017). When treating various disorders, psychologists incorporate diverse techniques and interventions in an attempt to target various treatment goals and individual aspects or characteristics of each client. This kind of approach to treatment could be considered competent and somewhat holistic as it attends to various needs of the client. Conversely, ABA neglects current research and data on children with Autism and does not attempt to understand it. Some of this research would include the autistic brain, access to MRI studies, or comorbid psychopathology associated with autism such as anxiety, Attention-Deficit/Hyperactivity Disorder (ADHD) and Obsessive Compulsive Disorder (Leyfer et al., 2006; Matson & Nebel-Schwalm, 2007; Muris, Steerneman, Merckelbach, Holdrinet, & Meesters, 1998). Of particular note, is the fact that research has consistently found higher rates of anxiety-related disorders among those with ASD when compared to their typically developing peers. (e.g. Bellini, 2004; Guttman-Steinmetz, Gadow, DeVincent, & Crowell, 2010) This may be in part due to the general over-activation of the Autistic brain which may contribute to abnormal levels of fear and anxiety (Amaral, Bauman, & Mills Schumann, 2003; Muris et al., 1998). Unfortunately however, this knowledge is neglected as Board Certified Behavioral Analysts (BCBA) implement behaviorist principles that are inappropriate to treat these comorbid disorders. They are essentially practicing out of their scope and without a license, with the hopes that ABA will somehow address both maladaptive behaviors and comorbid disorders. In traditional psychotherapy and/or with typical children, a therapist would not attempt to treat any anxiety-related disorders with ABA, yet it is acceptable to treat the nonverbal Autistic child with ABA. ABA is never prescribed to rid someone of anxiety but it can in fact create more anxiety along with a myriad of other issues previously discussed.

The operant conditioning and compliance enforced through ABA does nothing to address these symptoms and the many aspects of Autism in general. This kind of practice is inappropriate, irresponsible and abusive; furthermore, this approach to treating typical clients would never pass. Psychologists who have designed these ABA interventions and continue to recommend and advocate for these kinds of methods have done more than just a disservice to this population. Various other mental health professionals also continue to recommend and promote ABA treatment without any knowledge or consideration of what ABA specialists are actually doing. In 2017, one investment firm estimated that the market size for ABA services could be as high as \$17 billion annually, and with the continued creation of various ABA specialists, certifications, and programs that number is likely even greater now (Crocker Capital Advisors, 2017). With this kind of information is it evident what drives the continued use of these services, and how this vulnerable subset of children are not the primary focus. Given that the Behavior Analyst Certification Board (Behavior Analyst Certification Board, 2018) requires no education and training on Autism in general, let alone the cognitive and neurological characteristics of Autism, basic child development, social and interpersonal skills, cultural issues, child autonomy and self-esteem, dietary issues, etc., it is shocking that most have not questioned their current scope in working with children with Autism in the first place. The Behavior Analyst Certification Board's code of ethics mentions avoiding harmful reinforcers "that may be harmful to the health and development of the client,

or that may require excessive motivating operations to be effective” (Behavior Analyst Certification Board, 2018, p. 13). Without any training on child development or Autism, how would a BCBA specialist be able to identify this in the first place? Furthermore, to ignore the current research regarding negative impacts of this conditioning, as well as the presence of other modalities, and practicing outside of one’s scope is also a violation of the ethical code of conduct for both psychologists and BCBA specialists. (American Psychological Association, 2010; 2017; Behavior Analyst Certification Board, 2018.) In fact, future generations can compare this kind of abuse to the abuse we recognize in classic experiments and treatments from generations before us. Furthermore, psychology aims to help individuals and families to thrive, heal, and even reach what is referred to as “self-actualization” in some schools of thought. Without social interaction or the capacity to develop interpersonal skills, children become isolated and are unable to reach their human potential or self-actualization (Maslow, 1970). Long-term applications of ABA have failed the nonverbal ASD population in these areas and has even added insult to injury by creating more issues. Psychologists, like various other professionals, are charged with the responsibility to do no harm, and to “safeguard the welfare and rights of those with whom they interact professionally” (American Psychological Association, 2010, 2017). Considering their continued support, promotion and implementation of ABA treatment in the nonverbal population, how could one argue the negative effects of ABA are congruent with this oath?

In sum, when considering the lack of research on the efficacy of ABA in treating nonverbal children and the lack of research in support of long-term, intensive ABA therapy in the nonverbal population, as well as the lack of longitudinal research for an entire generation who have undergone this treatment, it is evident that we need to pause and look at what has resulted. It is important to read and to understand the research that is available, as it indicates negative effects surrounding the interventions and methods used in ABA therapy. Compliance, learned helplessness, food/reward-obsessed, magnified vulnerabilities to sexual and physical abuse, low self-esteem, decreased intrinsic motivation, robbed confidence, inhibited interpersonal skills, isolation, anxiety, suppressed autonomy, prompt dependency, adult reliance, etc., continue to be created in a marginalized population who are unable to defend themselves. ABA proponents have utilized predominantly non-verbal and neurologically different, children who are not recognized under this paradigm to have their own thought processes, basic needs, preferences, style of learning, and psychological and emotional needs, for their experiment. These children are the population that was chosen to be the subjects of an experimentally intense, lifelong treatment within a therapy where most practitioners are ignorant regarding the Autistic brain—categorically, this cannot be called anything except abuse.

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Author details

Aileen Herlinda Sandoval-Norton¹
E-mail: aherlindasandoval@gmail.com
ORCID ID: <http://orcid.org/0000-0002-7066-7041>
Gary Shkedy
E-mail: Gary@altteaching.org²
ORCID ID: <http://orcid.org/0000-0002-5422-9885>

¹ Clinical Director, Alternative Teaching Strategy Center, San Diego, CA, USA.

² Director of Research, Alternative Teaching Strategy Center, San Diego, CA, USA.

Competing Interests

The authors declares no competing interests

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