Applied Behavior Analysis: Clinical Efficacy, Autistic Perspectives, and the Research-Subject Polarization

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While much of the literature within therapeutic research related to those diagnosed with autism spectrum disorder (ASD) has brought about many different approaches, applied behavior analysis (ABA) is often the approach that receives the most attention. The behaviorist principles underlying ABA were written about and posited before they were introduced into the autism world with authors like B.F. Skinner laying the foundations for how humans operate within these principles and research practices within the field (Baer et al., 1968; Skinner, 1981). However, it was not until Dr. Ivar Lovaas at the University of California Los Angeles conducted his research on ABA as an intervention to establish behavioral and language skills in young children with autism from the mid-1960's into the late-1980's that this approach had a dramatic impact on autism research (Life, 1965; Lovaas, 1987). Much of Lovaas' early work is still influential on both the public perception of ABA as well as its implementation, and while some of the practices that Lovaas championed in specific instances have been all but disappeared from use, many of the principles remain (Bowman & Baker, 2014; Leaf et al., 2020). This history is critical because despite the seemingly gargantuan number of studies covering the subject of ABA from a practitioner standpoint, controversy has continued to steadily build within communities of autistic individuals about ABA and their experiences with the approach. Those writing for the Autistic Self-Advocacy Network (ASAN) claim ethical and identity issues related to the use of ABA, specifically stating how its ends are not to help autistic individuals reach fulfillment on their own terms but instead are to actively combat neurodiversity and shape them into those who can ultimately blend in and function like their typically-developing – or what I will refer to hereafter as "allistic" – peers (TNC, 2018). Even if the intent of behavior analysts may not lean

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actively in this direction, this concern is one to be taken seriously given the current stigma related to autistic individuals and their behaviors versus the community identity and positive attributes they gain from their diagnosis (Botha et al., 2020). This then begs a particular question: with everyone's experience differing tremendously as insiders or outsiders within the autistic community, how can this discrepancy be resolved despite the polar opposite views? Furthermore, can ABA be efficacious and beneficial for autistic individuals in ways that account for the potential detriment it may bring on self-determination and identity, and if so, how? These are each pertinent questions and are significant to explore within the literature of ABA and the perspectives of those who have experienced it.

Firstly, to establish the background and baseline of this argument, it is important to discuss what ABA in effect is and the literature surrounding its efficacy. ABA essentially relies on principles related to behaviorism like reinforcement and conditioning as a technique to not only build socially significant behaviors for overall development, but to reduce challenging behaviors like temper-tantrums and breakdowns that may impede learning and daily life (Baer et al., 1968; Myers et al., 2007). As a simple example, a behavior analyst could teach an autistic child to sit down for a predetermined period of time (30 seconds for instance) by rewarding them with food or a toy if they successfully manage to stay seated for a certain smaller period (e.g., 5 seconds) a specific number of times. By increasing the number of seconds that the behavior lasts over many trials and reinforcing continuously through rewards, the behavioral goal can be eventually reached. That technique, discrete trial training, has been used continuously within the autism literature due to its initial founding by Lovaas in 1965, though significant modifications have been made like decreasing the use of punishment towards autistic children (Bowman & Baker, 2014; Life, 1965; Myers et al., 2007). While exact practices within the field and specific

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priorities and techniques are somewhat variable given the individual learning goals of the child and the specific orientation and actions of the behavior analyst, much of the research generally suggests ABA being an efficacious therapeutic approach for those with ASD in several domains. Meta-analyses and reviews of the literature posit that ABA interventions can be effective in serving numerous areas of development and markedly improve intellectual abilities, expressive and receptive language skills, communication, and even in certain cases social behavior and adaptive living skills (Makrygianni et al., 2018; Matson et al., 2012; McPhilemy & Dillenburger, 2013). Furthermore, research has often touted what is known as Early Intensive Behavioral Intervention (EIBI) – a program where ABA is implemented over an approximately 25 to 40 hour per week regimen alongside caregivers – as being highly effective in building language and cognitive skills in young children with ASD under 3 years old, which is considered a critical learning period in development for both allistic and autistic development (Eigsti et al., 2011; Peters-Scheffer et al., 2011). Despite the supposed efficacy, even those in the literature that attest to ABA as a robust intervention state that these aspects are individualized and dependent on the context, child, and the learning goals, meaning that it becomes difficult to theorize the mechanisms as to why ABA seems to be effective for this population (Peters-Scheffer et al., 2011). Regardless, there are some potential theories that might explain some of the qualities that ABA exhibits when working with autistic children – mainly in language development. Autistic children are often theorized to have difficulties in interpreting and understanding theory of mind, which is the seemingly intuitive ability most allistic people possess to understand and interpret the intentions, motivations, and social cues of other surrounding them, which usually develops more concretely by the age of five (Baron-Cohen et al., 1985). Some have hypothesized that this difficulty is further exacerbated by more general language processing difficulties in those with

ASD, but others instead believe that these difficulties with theory of mind affect language acquisition reciprocally starting in infancy (de Villiers, 2007; Malle, 2002). This is believed to be because infants diagnosed with ASD tend to not engage in joint attention: the act of drawing the attention of another individual to an object socially through pointing, vocalization, and eye gazes (Adamson et al., 2019). Joint attention is often thought to be critical in demonstrating that an infant can not only understand that someone can have the intent to refer to an object in the world, but be able to connect labels to objects establish language. After all, if one cannot understand that another person has that intent and they possess knowledge different than oneself enough to know that someone is using a specific label to call an object, how can they know which verbal signals are connected to which objects? Therefore, if the theory of mind abilities important in establishing that joint attention are hindered in infancy, then it makes sense that those with ASD might have difficulties matching concepts and objects to their related referents (Adamson et al., 2019; Dawson et al., 2004; de Villiers, 2007). From this, if language development is being impeded by difficulties in theory of mind, then alternate routes of learning like ABA may be able to allow for this level of skill-building where discrete reinforcement and tasks are created. This may then both establish language skills while bypassing theory of mind difficulties and form fundamental skills that can help bolster further theory of mind performance later in development.

Even with this efficacy and potential theories laid out, there are many deep concerns from within the autism community related to ABA as a therapeutic approach. These concerns overall tend to stem from a belief that ABA comes from a biomedical and deficit-based perspective of autism in where individual traits related to autism are either replaced with behaviors against their wishes and feelings or are extinguished altogether to make them seem more allistic in nature (Gardner, 2017; Smart, 2009). While therapies by behavior analysts claim to be individualized

and based on context and learning goals, self-reports from autistic adults consistently describe being forced to modify outward behaviors and mannerisms and taught to be compliant or punished if not rather than teaching how to self-advocate or cope with sensory overload and emotional difficulties (Gardner, 2017). One particular example of suppressed behavior often cited from autistic individuals is that of self-stimulatory behavior – aka stimming – that can consist of hand-flapping, rocking back and forth, and other repetitive motor movements (Kapp et al., 2019). Literature within the field of autism treatment justifies their therapeutic focus on reducing stimming by claiming that it impedes learning outcomes based on the assertion that this behavior is indicative of the lack of ability in autistic children to attend to multiple relevant cues simultaneously within the environment (Cunningham & Schreibman, 2008; Turner, 1999). However, much of the research is mixed on to the exact reasons for why this connection exists and, importantly, tend to concurrently emphasize the social stigma associated with stimming as a justification for modifying that behavior. By contrast, research surveying autistic individuals demonstrate that while this behavior is indeed stigmatizing due to an allistic society, stimming serves as a self-regulation or coping mechanism during moments of sensory overload and heightened emotions that can allow them to not only express their feelings visibly, but regulate and process information better than if it were suppressed (Kapp et al., 2019). This difference in interpretation of behavior fuels the perspective that behavior analysts are acting according to biomedical models that favor changing autistic individuals to avoid stigma rather than challenge society and its stigma head-on and help autistic individuals reach fulfillment on their own terms. Another example where this stigma is pertinent is through modifying and teaching social interaction skills in ways that can imitate allistic individuals. While it may seem positive to implement behavioral interventions that can increase opportunities for social interaction, it can

increase stigma in ways that teach autistic individuals to camouflage their differences in processing social cues and thus decrease their self-esteem. This can be done via what is known as compensation, a process where autistic individuals form mental rules that allow them to comprehend social events (i.e., telling a difference between a joke and a lie based on if other people laugh or not) and modify their behavior to present as more allistic even if their social processing creates difficulties in fully capturing underlying social context (Livingston & Happé, 2017). This is a logical offshoot of the techniques and social skill learning often implemented in ABA, and while this may be adaptive in allowing autistic individuals to blend in, it can come at significant personal costs. Studies regarding compensation often find that this mechanism usually can only account for a certain level of nuance and can often break down in more socially complex situations (Livingston et al., 2018). Moreover, because these mental rules are more cognitive rather than implicit and require conscious effort and attention, they can often be exhausting to keep up and can end up leading to social anxiety when those rules end up breaking down – a finding that is consistent in self-reports of autistic individuals who compensate (Hull et al., 2017; Livingston et al., 2018). This anxiety and the stigmatizing of differences in social cues processing can lead to major mental health difficulties like depression and lower self-esteem, feelings of isolation and obligations to acquiesce to social norms, fear and hopelessness of being identified as autistic and rejected both socially and professionally, and beliefs that they cannot be true to themselves and others (Hull et al., 2017). This stigma within the literature is cited within numerous areas as being part of the way that autistic people experience the world, and yet, they often state their pride and the value they have in being autistic and the positivity, empowerment, protection, and belonging that comes with that label and the community membership associated with it (Botha et al., 2020; Gardner, 2017; Kapp et al., 2019; Nario-Redmond et al., 2013). This

socio-political view and its benefits within this population further create a contrast between behavior analyst goals to change behavior as the purported benefit of autistic people and the voices of those within the community who strongly oppose it, which begs the question: should an outdated, biomedical view be the ultimate goal of ABA? This point might be subjective, but even if it were not, other research in the literature challenges the efficacy of ABA as an intervention in complex social areas. Some studies cite how much of the literature surrounding effectiveness cites not just the shift in ethical standards based on increasingly positive views of autistic behaviors, but difficulties in demonstrating compelling evidence due to lower quality standards of research practice and design and present limited or inconsistent information regarding socially significant improvements (Mottron, 2017; Warren et al., 2011). Furthermore, the techniques of reinforcing in autistic children are sometimes linked to over-compliance and dependency on social prompts and reinforcement that makes it difficult to operate in socially effective ways when interacting with others, thus impacting social skills and self-esteem in children and adults (Sandoval-Norton & Shkedy, 2019). Even a report from the U.S. Department of Defense cited evidence that ABA interventions resulted in little or no significant clinical change in symptomology and may have resulted in a small number of individuals undergoing ABA to regress in terms of symptom progress (Stewart, 2019). With all these aspects in mind, it calls into question not just if ABA as an approach is effective on its own of accomplishing its goals, but if its goals of changing autistic behaviors for the sake of allistic ends is justified on principle.

What makes this clash between perspectives so polarizing and ambiguous is that while any decent researcher believes in scientific efficacy and evidence-based practice, findings and clinical orientations that people gravitate towards are still inherently based on personal interpretation and bias. For autism research this is especially relevant given the difference

between the biomedical, deficit-based perspectives that seem to define the field of ABA and the sociopolitical and cultural perspectives of self-advocates within the autism community. This is no more apparent than in the case of researcher Henny Kupferstein – a researcher who not only is autistic, but is the mother of autistic children as well. In 2018, Kupferstein conducted and published a study regarding the potential effects of ABA on autistic individuals and how it might relate to symptoms of post-traumatic stress disorder. She relied on online surveys conducted with individuals in the autism community as well as parents of young autistic children as well as self or caregiver report measures of PTSD symptoms and autistic traits. Through this, she found a positive association in autistic individuals between those who were exposed to ABA treatment and heightened reported PTSD symptoms, with this difference being more prominent in autistic adults who had received ABA in comparison to children (Kupferstein, 2018). This finding is consistent with some of the experiences that autistic individuals self-report in their time undergoing ABA therapy, and if true presents a serious challenge to the ethical standards of ABA practice (Gardner, 2017). To counter this argument, researchers Justin Barrett Leaf and company the same year cited Kupferstein's data as being questionable given the nature of selfreports being biased towards individual perception and not being indicative of objective data, especially when autistic and PTSD symptoms are clinically diagnosed through means other than self-report. The researchers felt that bringing this claim into the light without sufficient evidence would reduce the level at which parents would adopt efficacious therapeutic approaches, thus hindering the likelihoods of autistic children to overcome their challenges (Justin Barrett Leaf et al., 2018). Despite this claim, a third group of researchers submitted a letter to the editor of the journal that both articles resided in, Advances in Autism, criticizing Leaf et al. (2018) and their approach to criticizing Kupferstein's research (Chown et al., 2019). They stated that

Kupferstein's research claims still may have weight despite her methodological difficulties and that her self-report data could be accounted for her conducting this research independently without funding and on her own time, thus showing her rigor in the research despite these constraints. More importantly, they cited that funding for Leaf et al. (2018) was provided by both the Association for Behavior Analysis International and an anonymous donor who stated their support for ABA interventions for those diagnosed with ASD, arguing a potential conflict of interest that may demonstrate hypocrisy in Leaf's criticism of the rigor of Kupferstein's research (Chown et al., 2019). This struggle between an autistic researcher advocating for those in her community and the research interests of those passionate about behavioral therapy demonstrate the deep polarization between the priorities of both communities. Both communities want to help and try to increase the quality of life of autistic individuals, but each have diametrically opposed understandings of ASD and philosophies on how to bring about their vision. Those who are behavior analysists might work with autistic children who present with self-injurious behavior and co-occurring intellectual and developmental disabilities that make independent living and learning markedly more difficult in comparison to those who are labeled as higher functioning, therefore skewing their perceptions. On the other hand, autistic individuals who can function and adapt to social skills closer to allistic individuals may see the difficulties that those like them face and the feelings of having to suppress their differences and not embrace their own identity, thus creating a different but similarly skewed definition. What is autism at its core? What does a "higher quality of life" look like for an autistic individual? And ultimately, what should the end be in trying to help autistic people thrive best and at their happiest: biomedical or sociopolitical? In all honesty, it is deeply hard to say. Every autistic person and every therapist is unique, and while each one will take in evidence through the research, their personal experiences with ASD

and its differences will inevitably influence their personal perceptions. Thus, it becomes extremely difficult to discuss specificities of techniques and exactly what contributes to the difficulties that ABA might bring because therapists and the autistic community disagree ultimately on what the ends are. Should they be to change society to be more accepting of autistic individuals and their merits, or should it be to help give autistic people the tools to adapt and live seemingly happily in a world that seems made for those unlike them? While I have my own answer and interpretation given my experience as an autistic person, there is no single objective, straightforward answer due to the nature of research, its biases, and the interests of those in these research communities.

Regardless of how muddy and complicated the territory can be in terms of ABA and its efficacy and effects on autistic individuals, there are still modifications that can be made to ABA in order to address at least some of these issues. Firstly, as mentioned above, since there are some theories as to how ABA can help bypass difficulties in acquiring language, implementing it in ways that are beneficial to overall language and communication rather than focusing on social skills and imitation may allow for later skills to be built upon those foundations. In the ABA field, this phenomenon – known as a behavioral cusp – could be significant in helping autistic children adapt and form social skill understanding rather than mere imitation by giving them baseline communication in ways that allow them to more naturalistically develop other related socialization behaviors spontaneously (Rosales-Ruiz & Baer, 1997). This can even be implemented in language therapy in ABA through a method called incidental training, which abides by ABA procedures but does so in naturally occurring environments and are based upon the interests and initiations of the child rather than mandated completely by the therapist (McGee et al., 1999). This in tandem with behavioral cusps can result in more spontaneous language

acquisition and social interaction in autistic children while likely allowing for more freedom within interaction rather than behavioral definitions and constraints of neurotypical interaction (Charlop-Christy & Carpenter, 2000; Robinson, 2018). Secondly, given Kupferstein's research regarding PTSD as well as reports from individuals regarding the traumatizing and punitive nature of ABA, focusing on training related to trauma-informed for licensed behavior analysts may prove to be beneficial in providing therapies that allow autistic individuals to gain skills important to their development without inadvertently inflicting trauma through forcing skills not conducive to the client's happiness and self-esteem. Researchers within the ABA literature like the aforementioned Justin Barrett Leaf hearken to this notion in stating how the field has moved past punitive techniques and more towards understanding the motivating operations behind behavior in order to allow for developing more accurate and effective behavioral approaches depending on the individual (Justin B. Leaf et al., 2020). Lastly, some research indicates that while ABA is often seen as a comprehensive program for autism therapy, it may be more effective and socially valid to integrate its techniques with other therapies like TEACCH, which incorporate visual schedules and environmental structures in order to address challenges and facilitate more productive communication in autistic children (Callahan et al., 2010). Integrating and allowing for improvement through a multitude of therapeutic approaches may allow for therapies that target individual differences and priorities more effectively, thus reducing the likelihood that these approaches would encroach on the unique expression of the autistic individual and their processing of the world. However, none of these are still clean wins or provide easy answers. These approaches still have to be augmented by a genuine discussion between researchers and the autistic community about what the priorities in therapy should be,

defining what autism is within these communities and what it can be, and ultimately seeing what it means to help autistic people live the happiest lives possible, whatever they happen to be.

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