

Engaging with Autistic Perspectives on ABA: Response to Leaf et al., 2021

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Abstract

In this commentary, we respond to a recent article published by Leaf and colleagues (2021), entitled “Concerns About ABA-Based Intervention: An Evaluation and Recommendations”. In their article, the authors attempt to address concerns raised by autistic people about ABA-based interventions. We argue that they only superficially engage with these important issues, and fall short of supporting neurodiversity, despite their intention to do so. We discuss issues related to biased claims of effectiveness of ABA, the potential for ABA-based interventions to cause harm, the reliance on past human rights abuses to justify current potential for harm, a lack of empirical support related to intervention intensity recommended by ABA provider groups, and the rigidity of procedures used to achieve therapist-determined goals.

Keywords: Applied behavior analysis, autism, neurodiversity, adverse events, intervention efficacy, autistic perspectives

Introduction

Recently, Leaf and colleagues (2021) published a commentary aimed at addressing concerns raised by autistic people about ABA-based interventions, and proposing potential paths forward for ABA researchers and practitioners. We applaud the authors for seeking out and engaging with the work of autistic people, and wish to see more researchers and professionals make this effort in the future. However, while the authors claim to support the neurodiversity paradigm and to value the input of autistic people, we argue that they instead dismiss reasonable concerns with partial and misleading evidence. Below, we discuss several major claims made by the authors, and indicate how their responses fall short of adequately engaging with autistic people's critiques of ABA.

Biased Claims of Effectiveness

Much of the commentary hinges on the assertion that ABA-based interventions have strong empirical support, citing a “plethora” of evidence. However, recent reviews that account for adherence to quality standards have found no such evidence (Rodgers et al., 2021; Sandbank et al., 2020). Over its more than 50-year history, behavioral researchers have produced too few randomized controlled trials of ABA-based intervention for autistic children that adhere to basic quality standards (e.g., adequate randomization procedures, masked assessors) to permit statistical synthesis of findings (Sandbank et al., 2020). While some organizations do categorize ABA as an ‘evidence-based practice’, we note that there is little agreement on the definition of this term, and that the amount and quality of evidence required for such a designation is exceedingly low. For example, the National Autism Center Report (produced by the May Institute, an organization that also provides ABA services) assigns this designation based on the number of studies that meet only minimal quality indicators, and provide no assessment of the

quality of the outcome variable. As such, intervention studies with limited internal validity, and/or that show narrow and temporary change on outcome measures that were not subject to construct validation are deemed ‘evidence-based’ (Sandbank, Chow, Bottema-Beutel et al., 2021).

Other research has found that a majority of ABA-based intervention studies with autistic participants are conducted by researchers who are also ABA clinical providers, and this conflict of interest (COI) is disclosed in less than 2% of published research reports (Bottema-Beutel & Crowley, 2021). It is illustrative that, despite the fact that at least five of the commentary authors are employed by an agency that provides training to ABA clinicians, the original COI disclosure statement reads “None of the authors have any conflict of interests with this commentary”.

Following an inquiry to the *JADD* editor by a fellow researcher, the statement was revised to acknowledge author affiliations with the Autism Partnership Foundation (Leaf et al., 2021).

Notably, the revised statement still fails to disclose other significant COIs, such as co-author Lorri Unumb’s role as CEO of the Council of Autism Service Providers, an organization that advocates for ABA practitioners. The high prevalence of COIs among ABA researchers and the failure to properly account for them, coupled with an evidence base lacking in quality, leaves us skeptical of the trustworthiness of Leaf and colleagues’ conclusions regarding the effectiveness of ABA on meaningful outcomes for autistic people.

Potential for ABA-based Interventions to Cause Harm

Several sections of the commentary are devoted to addressing autistic people’s concerns that ABA interventions are abusive, harmful, and associated with negative long-term outcomes. To minimize these perceptions, Leaf and colleagues clarify that Lovaas, who advocated shocking, slapping, and convincing autistic children that he would kill them (Chance, 1974),

only used aversive procedures in response to self-injurious behavior. They also cite a lack of evidence documenting short or long term adverse effects of any ABA procedures, including aversives and extinction protocols. However, as Dawson and Fletcher-Watson note (2021), even procedures that are not traditionally associated with abuse, such as the provision of food reinforcers and planned ignoring, have the potential to cause long-term harm. A recent review of adverse event reporting supports the authors' assertions regarding the scarcity of evidence; adverse events are rarely systematically monitored or reported in autism intervention literature (Bottema-Beutel et al., 2021). However, this lack of reporting is a serious ethical violation on the part of autism researchers. We find it striking that this oversight would be used to minimize concerns regarding potential harms rather than be taken as an acknowledgement that there is little information available to make an informed choice regarding whether participation in ABA intervention is worth the risk of harm given purported benefits (which, as argued above, have not been adequately established).

It is unclear to us how autistic people, especially autistic non-researchers, would be able to produce the evidence the authors require in order to take their concerns about ABA-related harms seriously. Although Leaf and colleagues do call for increased reporting of adverse events in primary ABA research, they also direct practitioners to be "compassionately skeptical" when faced with claims from autistic people about potential long-term negative outcomes. We find this egregious. Not only is there a pervasive lack of basic ethical compliance in regards to monitoring and reporting adverse events, the authors minimize the only form of evidence autistic non-researchers could be reasonably expected to produce given the failure of ABA researchers; their own experiences.

Leaf and colleagues also reference the scarcity with which extreme aversives are currently used to modify behavior, as a means to downplay the seriousness of this practice. In fact, within days of their commentary being published, the Federal Drug Administration in the US reversed a ban on electric shock procedures, which have been deployed by staff at the Judge Rotenberg Center in Canton, MA to modify the behavior of disabled people (Pierson, 2021). The ban reversal means that what is essentially torture will continue to be acceptable procedures for the people who live at the center, many of whom are autistic. We think it is noteworthy that the Association for Behavior Analysis International (ABAI), an ABA membership organization that disseminates ABA journals and accredits BCBA training programs, provides a yearly platform for Judge Rotenberg Center-affiliated professionals to defend and promote the use of electric shocks at their annual conference. Even if Leaf and colleagues do not condone the use of shocks as part of behavioral therapy (their position is unclear), the ABA community writ large has done little to stop it.

Historical Mistreatment of Autistic People Does not Justify Current Mistreatment

The authors purport that ABA-based interventions have improved the quality of life for autistic people. However, we are unable to locate any behaviorally-based experimental studies that measure autistic people's quality of life as an intervention outcome, despite calls to do so (Schwartz & Kelly, 2021). Rather than relying on empirical evidence, the author's assertion rests on a comparison of current conditions for autistic people to a long history of human rights abuses, stating that "...[autistic] children were literally dying or experiencing 24 hour restraint to keep them from harming themselves, and many were destined to spend their entire lives in an institution (Koegel, 2015)". The authors frame these conditions as an inevitable circumstance for autistic people (e.g., they were "destined"), without providing historical details regarding links

between medicalized perceptions of autism and ableist ideologies that made institutionalization and abuse commonplace. Lovaas' scholarship was very much aligned with medical-model conceptualizations of autism (Schwartz & Kelly, 2021) that are still referenced in arguments *for* institutionalization. In fact, there are multiple residential institutions in operation today that market themselves as ABA providers and are run by applied behavior analysts, such as the aforementioned Judge Rotenberg Center, the New England Center for Children, and the May Institute. Institutionalization remains an outcome for autistic people at least in part due to behavioral treatment approaches that occur in such settings.

While the authors credit Lovaas' work in allowing for autistic people to live outside institutions, the history of deinstitutionalization involves a complicated set of factors including changing ideologies that pre-dated widespread availability of ABA, including parent- and autistic self- advocacy, and legislative changes- not simply the availability of services that could be provided in the home (Eyal, 2013). Whatever the historical role of ABA in deinstitutionalization of autistic people, the occurrence of past abuses does not absolve autism professionals-- of any disciplinary orientation-- from monitoring, understanding, and minimizing harms that can be linked to their current practices.

Lack of Support for Intervention Intensity

The authors address concerns about the intensity of ABA-based interventions recommended and provided to young autistic children, by construing them as a misconception; 40 hours per week of ABA intervention is not provided to *all* autistic children who receive ABA services. However, the autistic author of the piece articulating this concern (Lynch, 2019) references a quote from Lovaas himself setting the 'standard' dosage at 40 hours per week. The Lovaas Center, which advertises itself as a continuation of Lovaas' work, (mis)states on its

website: “Empirical research has shown that 35-40 hours per week of one-to-one instruction is the most effective strategy in improving outcomes” (The Lovaas Center, n.d.). Similarly, the Behavior Analysis Certification Board promotes up to 40 hours per week of ABA intervention in its guidelines and refers to this dosage as common and necessary: “... intensity levels of 30-40 hours per week are common and necessary to achieve meaningful improvements in a large number of treatment targets” (Behavior Analysis Certification Board, 2019). Even if not *all* autistic children receive 40 hours per week of ABA-therapy, this level of intensity is certainly promoted by ABA organizations, and likely provided to many autistic children despite little supporting evidence (Pellecchia, Iadarola, & Stahmer, 2019). While Leaf and colleagues cite several meta-analyses as evidence for a relationship between intervention intensity and child outcomes, these meta-analyses include low-quality studies that are subject to a variety of biases (e.g., the Edevik et al., 2009 meta-analysis cited by the authors included only a single RCT). Primary studies and quality-controlled meta-analyses that statistically test intensity as a moderator of outcomes have not found a relationship between intervention intensity and child outcomes (Choi et al., 2021; Sandbank, Bottema-Beutel, & Woynaroski, 2021; Rogers et al., 2021).

Goal Selection and Attainment

Autistic people have voiced concerns that the goals pursued in ABA therapy encourage autistic people to mask behavioral proclivities that are either benign, and/or serve important functions (e.g., rocking or flapping for self-regulation) (Dawson & Fletcher-Watson, 2021). Leaf and colleagues argue that ABA therapists select goals that are meaningful to society, and prepare autistic people to live in an ableist world. We counter that autistic people have historically been excluded from social processes that determine what is “meaningful to society”, and therapies that

promote extinguishing autistic behaviors only perpetuate their exclusion. Pathologizing autistic behavior as inherently in need of treatment *produces* and *maintains* ableist conceptualizations regarding social acceptability (Goffman, 1963), and encourages parents to focus on ‘fixing’ their autistic child rather than adopting acceptance and support models to adapt to life post-diagnosis. In addition, many autistic people report that masking their behavior is accompanied by anxiety and stress (Cage & Troxell-Whitman, 2019), suggesting that there is a cost to suppressing autistic traits that is not counterbalanced by social inclusion (Mandy, 2019).

Concerns have also been raised about the rigidity of procedures used to achieve goals developed in ABA programs, and whether or not this reflects an optimal learning environment for autistic people (Nader et al., 2021). Strangely, Leaf and colleagues argue that ABA therapy does not use rigid procedures, and that Lovaas himself decried the use of protocols. However, fidelity checklists (i.e., protocols) are standard components of ABA experiments and case reports (Ledford & Gast, 2018), and a variety of common ABA techniques, such as discrete trial training (DTT), require the use of rigid protocols. Even if ABA therapists are encouraged to exercise creativity and improvisation in their work, as Leaf and colleagues claim, autistic children who participate in ABA are rarely granted such freedom. Instead, ‘correct’ responses are pre-determined, rigidly operationalized, prompted, and reinforced by the therapist-- despite the fact that autistic people have shown success in designing their own strategies to improve health outcomes (Pavlopoulou, 2020). Some ABA proponents do advocate for a revised version of ABA that combines behavioral techniques with developmental principles, and child-led learning opportunities that are less rigid than traditional ABA techniques (Schriebman et al., 2015). However, a survey of ABA professionals found that very few respondents were able to define

these practices, and many considered them outside the scope of ABA service provision (Hampton & Sandbank, 2021).

Conclusion

In summation, although the authors claim at the outset of their commentary that they are in support of the neurodiversity movement and wish to address concerns made by autistic people in good faith, we feel that they have fallen far short of this goal. In order for a productive path forward, ABA researchers and providers need to more seriously consider: (1) autistic people's concerns of harm based on their experiences participating in ABA, (2) rigorous scholarship that counters claims of ABA's effectiveness, (3) the ableist roots of ABA as a clinical practice, and (4) the failings of ABA researchers who have not monitored or reported adverse events, and produced scholarship with unacknowledged conflicts of interest.

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