RESPONSE TO COX ET AL

**The Role of Compassion and Ethics in Decision-Making Regarding Access to
Applied Behavior Analysis Services During the COVID-19 Crisis: A Response to**

Cox, Plavnick & Brodhead

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Abstract

Cox, Plavnick, & Brodhead (2020) published a position statement in the emergency section of BAP in response to the COVID-19 crisis. They argued against a blanket interpretation that in-person ABA services for all patients should continue during the COVID-19 pandemic. They strongly argued that the risks of continued services are almost always prohibitive and that only in rare cases would continuation of in-person services be warranted. Columbo, Wallace & Taylor (2020) soon thereafter published a response to the article pointing out the potential dangers associated with the position and paper of Cox et al. They included a detailed decision model to assist providers in making nuanced and informed data-based decisions that provide the opportunity to honor the ethical responsibility for not abandoning patients. We echo the importance of the Columbo et al. response and add points of response centered on balanced ethical decision-making informed by compassionate family-centered care.

Keywords: compassion, COVID-19, decision-making, ethics

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Editor's Note

This manuscript is being published on an expedited basis, as part of a series of emergency publications designed to help practitioners of applied behavior analysis take immediate action to adjust to and mitigate the COVID-19 crisis. This article was submitted on 4/25/20 and received final acceptance on 05/12/20. The views and strategies suggested by the articles in this series do not represent the positions of the Association for Behavior Analysis, International or Springer Nature.

Introduction

Cox, Plavnick & Brodhead (2020) published a position statement in the emergency section of BAP in response to the COVID-19 crisis. The authors offered a potential framework for practitioners to use when making clinical decisions based on the premise of reducing the spread of COVID-19. They argued against a blanket interpretation that in-person applied behavior analysis (ABA) services for all clients should continue during the COVID-19 pandemic. We agree with the authors that the nature, scope and dosage of ABA services should be made on an individual basis for each patient (our preferred term for this paper). Indeed, individualized plans for medically necessary ABA services are always necessary, regardless of the circumstances. While we appreciate the authors' attempt to rapidly disseminate guidance to behavior analysts during this unprecedented time, we respectfully disagree with several of the other points made by Cox et al. (2020). Given the complexity of this practice issue, we are concerned about the impact of the proposed decision-making model on the long-term health and

well-being of families and their children. There are several family-focused considerations missing from their risk analysis, and their strongly worded language can be interpreted as overly advocating for discontinuation of in-person services rather than balanced towards the optimal decision for an individual family, with input from that family.

As noted by Cox et al. (2020) the currently available information will lead to changes in considerations, and they invite colleagues to identify gaps in their logic to improve upon the decision-making process. Columbo, Wallace & Taylor (2020) soon thereafter published a response to the article pointing out the potential serious negative consequences associated with the arguments of Cox et al. They included a detailed decision model to assist providers in making nuanced and informed data-based decisions that provide the opportunity to honor the ethical responsibility for not abandoning patients. We echo the importance of the Columbo et al. response and heartily agree with many of their points. We also have several additional points of response centered on the importance of balanced ethical decision-making informed by a compassionate and family-centered approach to care.

Let us begin by reiterating support for Columbo et al. in addressing several issues in the Cox et al. (2020) paper. First, Columbo et al. cogently illustrate the potential dangers associated with questioning whether in-person ABA service providers are essential personnel (and by implication providing essential services). When the Patient Protection and Affordable Care Act (ACA) was signed into law in 2010, behavioral health treatment was specified as an essential health benefit, and a majority of states include ABA specifically within the scope of essential health benefits. Prior to COVID-19, ABA has been deemed as an ‘essential healthcare treatment’ by the State of California Department of Insurance (DOI, 2011). In addition, several states have released COVID-19 guidance from healthcare officials stating that behavioral health providers

are essential personnel during this pandemic (Bowen, 2020). Neal Bowen, Director of the Behavioral Health Services Division of New Mexico, states “*it is more important than ever to continue to make available the unique support, guidance, therapy, and direction, to all of our neighbors, that Behavioral Health professionals are trained to deliver*” (p.1). Columbo et al. accurately describe the significant dangers associated with introducing unnecessary doubt about whether ABA service providers should be considered essential personnel. Rather than questioning *whether* ABA providers are essential, we argue that the relevant issue at hand is how to address the variables influencing the providers’ ability to safely provide continuity of care for families using any type of service delivery modality, including telehealth. We refer the reader to the recently published CASP (2020) *Practice Parameters for Telehealth-Implementation of Applied Behavior Analysis: Continuity of Care during the COVID-19 Pandemic*, which provides extensive guidance for selecting appropriate models of telehealth and evaluating the effects of transition to telehealth, as well as Rodriguez (2020) for a matrix for assessing readiness and appropriateness of various telehealth formats.

Our primary concern is that Cox et al.’s decision-making model appears to take the approach of first discontinuing care, then evaluating the parameters of care *only if* requested through the following guidance “*If the client or the client’s legal guardians have not requested for services to continue, then services should stop until the COVID-19 pandemic subsides*” (Cox, et al, 2020, p. 9). High quality ABA service providers should never make the decision to discontinue care without discussing it with the patient and patient’s family first. It is possible that the authors assumed providers had started with this conversation before beginning the decision model. However, without giving explicit direction on the process of communicating with the patient’s family first, the article can be interpreted as recommending to simply discontinue

services for families who did not already spontaneously request the provider to *not* discontinue in the past. If providers interpreted the article as recommending this approach and the providers then took this approach, it would add an unreasonable burden on the family to request services to continue in any modality (i.e., in-person or via telehealth), rather than being protected in their right to have a reasonable continuity of care for their loved one. As directly stated in our code, behavior analysts act in the best interests of the client and supervisee to avoid interruption or disruption of service. It also states that behavior analysts make reasonable and timely efforts for facilitating the continuation of behavior analytic services in the event of unplanned interruptions (e.g., due to illness, impairment, unavailability, relocation, disruption of funding, disaster) (BACB, 2014; 2.15). Rather than making the family request the first step in determining whether to proceed with care, providers should first be asking *how* they can safely offer continuity of care using any of the available modalities.

The recommendations and analysis of Cox et al. (2020) would be improved by specifically recognizing the circumstances of families of children with autism and emphasizing compassion for their potentially dire circumstances during this crisis. Without more explicitly acknowledging the plight of families in their article, the following quote can be interpreted as minimizing the involvement and independent decision-making of families in determining care options for their child: *“The blanket interpretation of ABA as an essential service is a major concern if it results in ABA providers continuing to provide in person services for all clients they serve, or for all clients or ABA consumers who request that services continue”* (pg. 5). One could argue this verbiage connotes a traditional “expert model,” where the provider has the decision-making authority and the family must or even might be *“forced”* (p.9) into receiving services for their children, and thus forced into risk. Families are already in the position of having sought

and, often fought for, access to treatment services for their child before ever coming into contact with their provider. Thus, there is sufficient reason to believe that families should have a voice in their access to behavioral health services. On one hand, the first step in the Cox and colleagues decision model does refer to the family's desire regarding in-person services. On the other hand, the lack of direct discussion in the text of the process of communicating with families deemphasizes the importance of this critical ethical priority. When families desire to continue with in-person care, it is imperative that practitioners seek informed consent to continue treatment during the pandemic. For many families, continued access to services is critical; without robust educational services and limited ability to provide continuous care for their child, the long-term prognosis may hinder overall outcomes and quality of life.

The authors seem to minimize the harm that could occur with respect to loss of treatment gains due to extended interruption of services, and do not speak to the literature on optimizing learning outcomes for children with autism (Eldevik et al., 2010; Eikeseth, Smith, Jahr, & Eldevik, 2007; Howard et al., 2014). The critical timeframe and recommended number of hours are still important regardless of a pandemic. Cox et al. (2020) seem to suggest that only individuals with severe problem behavior that would threaten their health, or the health of a family member, would warrant continuation of in-person services. This recommendation stands in contrast to the known importance of development and maintenance of functional communication and adaptive skills as well as the likelihood of regression in skills due to the interruption of services. The authors acknowledge that their recommendations “*may negatively affect the positive trajectories of individuals with ASD*” and this may lead the reader to interpret the authors' statement that the risk of skill of regression is minimal over the potential spread of COVID-19. The authors go on to state that the “*risk associated with all ABA consumers must be*

accounted for on an on-going basis” (p. 14), with which we agree. With respect to this continual evaluation, shelter-in-place orders and phased reintroductions will likely extend well beyond a temporary 3-6 week duration and researchers from Harvard estimated prolonged or intermittent social distancing into 2022 (Kissler et al., 2020). Children who lost access to services for even half of that time might be harmed by the delay in treatment. This pandemic and beyond is an impetus to determine the method of treatment that is both safe for the patient and the practitioner with all parties understanding the long-term risks and benefits. In doing so, we suggest that not one variable is more or less important than the other (i.e., regression vs. spread of infection) as one strives to achieve an ethical balance in decision-making.

Beyond the risk of regression for the individual child, we also must consider the family as a whole and the potential for significant increases in mental health concerns for patients and their families. Families who care for children with ASD experience higher levels of stress than those with any other developmental disability, leading to increased rates of mental and physical health concerns (Abbeduto et al., 2004; Bitsika & Sharpley, 2004; Benson & Karlof, 2008; Dunn et al., 2001; Estes et al., 2009; Hayes & Watson, 2013; Khanna et al., 2012; Rao & Beidel, 2009). Moreover, parental well-being has been found to strongly relate to child behavior (Davis & Carter, 2008; Hastings et al., 2006; LeCavalier et al., 2006; Osborne et al., 2007; Rayno & McGrath, 2006). As behavior analysts, we have the responsibility to advocate for the appropriate amount and level of service provision and oversight required to meet the defined behavior-change program goals (BACB, 2014; 2.09), and therefore, we caution the authors in making strong and global statements that may have a larger-scale impact for a significantly longer duration than initially estimated. The stresses that led the family to seek ABA in the first place

do not go away during these trying times. In fact, these stresses likely increase with the multifaceted challenges of the COVID-19 emergency.

The detrimental effects of loss of services go beyond the family unit itself. Parents who are unable to work because of the loss of assistance in managing their child's behavioral health condition may cease making their own contributions to society. For example, ABA providers are serving children of first responders and other healthcare professionals who are actively treating COVID-19 patients. Those professionals may be able to continue supporting the healthcare community only with continued ABA treatment. If ABA services are suddenly withdrawn, parents may have to severely restrict their focus on other family and societal demands to manage the complex, potentially severe, and now untreated behaviors and deficits that led them to seek ABA services in the first instance, thus further increasing the strain on the healthcare system.

Another opportunity to provide a more comprehensive risk evaluation proposed by Cox et al. (2020) would include consideration of safety practices that could be put into place for in-person services. First, providers can openly communicate the practice's standpoint on treatment during COVID-19. For example, a provider should clearly communicate that if a patient or family member residing with the patient is diagnosed with COVID-19, treatment will need to be placed on hold until the individual has recovered. Second, the number of patients and others with whom providers come into contact can be limited with appropriate planning (e.g., each patient might be assigned a single technician for person-to-person services). Third, safety precautions and protective equipment could be used in accordance with published recommendations for when individuals need direct personal care services or when individuals have to be in public to serve their essential function.

Rather than discontinuing ABA services, ABA in-person service providers can, under some circumstances, continue to provide services in the context of a limited number of providers per patient and with full personal protective equipment. The authors state that ABA providers *“Are likely to be unaware they have it and will be unaware they are spreading the disease to others”* (p. 5). While this is certainly possible and would be concerning if true, this is equally possible for with other service providers (e.g., pediatric office, first responders). It is reasonable to assume that standard healthcare screenings (e.g., testing for fever) could be put into place for ABA services just as they are for many other essential services providers.

In the instance that families do want to pause services, temporarily or for an extended period of time, practitioners should continue to follow our ethical code by informing families of the risks and benefits of continuing and not continuing treatment and honoring their decision. For example, if a patient was seeking treatment for cancer and decided to discontinue care, the healthcare provider is ethically required to discuss the risks and benefits with the patient. The patient signs consent forms understanding those risks if they discontinue treatment. As a final point of concern, the recommendation that services be stopped if the family does not have access to technology for telehealth -- *“if barriers are technological...ABA services should be temporarily suspended while the infrastructure for remote service delivery is put in place”* (p. 10) -- is problematic as it disadvantages lower socioeconomic status families in comparison to higher-income families. Losing necessary ABA services might put families' livelihoods or productivity at risk even if services are unavailable for a short amount of time. There will be an unacceptable disparity in access to treatment if only those who have access to wifi or a smartphone are able to continue services.

In summary, the authors are well-known and respected for their expertise in ethics within the field of behavior analysis and we appreciate all their contributions to our field. Unfortunately, due to the need to quickly disseminate guidance to our field, we believe that many strong, global statements were made without healthcare data to inform their assertions. The risk of making these statements in a published article in a behavior analytic journal is that practicing behavior analysts might assume that the statements are as data-based as those made in the conclusions of experimental studies. For example, the authors directly recommend that *“most in-person services be temporarily paused....even if ABA providers are not in a jurisdiction currently under a shelter at home order (p. 10).”* It is not uncommon for readers to interpret a word like “most” as functionally similar to “all,” in which case this statement appears contrary to their primary recommendation that decisions should not be made in a blanket, non-individualized fashion. Put simply, the word “most” may actually direct readers *away* from making decisions on an individual basis, which is the very point of the Cox et al. article. Part of the individualization process for determining care should incorporate the specific legal guidance from state governments (BACB, 2014; 1.05) and published public health recommendations for essential providers which include increased hygiene practices, daily health screenings for all staff/family members, limitations on travel, family and staff attestations about exposure/symptoms, increased sanitization protocols, reduced social contact by moving to a one-person treatment team model to minimize exposure across staff and families (BACB, 2020). The recommendation to pause care for most families could easily be interpreted as failing to address the considerations described above, particularly for those families who do not have a shelter at home order.

Indeed, the Centers for Medicare and Medicaid Services (CMS) have acknowledged that home and community-based services (HCBS) provide critical support (Medicaid, 2020). These

services enable people with intellectual and developmental disabilities to live in their home or community. CMS has encouraged states to ensure that resources are available through a number of avenues, including the expansion of service settings to private homes for services typically delivered in facilities and expanding the use of telehealth service delivery (Edwards, 2020).

We must not forget the purpose of our applied science (i.e., to improve lives in socially meaningful ways) and the needs of the people we serve in the face of a pandemic. Our response during COVID-19 will be a defining moment. The decision on when and how to deliver treatment should be individualized, in collaboration with the patient and family, and follow the laws of the local, state, and federal governments. As behavior analysts, our response should be one of balanced ethical decision making informed by compassionate, family-centered care for families.

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