# Ethical Concerns with Applied Behavior Analysis for Autism Spectrum "Disorder"

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# §1 INTRODUCTION

This paper has both theoretical and practical ambitions. The theoretical ambitions are to explore what would constitute both effective and ethical treatment of Autism Spectrum Disorder (ASD). However, the practical ambition is perhaps more important: we argue that a dominant form of Applied Behavior Analysis (ABA), which is widely taken to be far-and-away the best "treatment" for ASD, manifests systematic violations of the fundamental tenets of bioethics. Moreover, the supposed benefits of the treatment not only fail to mitigate these violations, but often exacerbate them. Warnings of the perils of ABA are not original to us—autism advocates (e.g., Devita-Raeburn 2016, Sparrow 2016) have been ringing this bell for some years. However, their pleas have been largely unheeded, and ABA continues to be offered to and quite frequently pushed upon (see §3.3) parents as the appropriate treatment for autistic children. Our contribution is to argue that, from a bioethical perspective, autism advocates are fully justified in their concerns—the rights of autistic children and their parents are being regularly infringed upon. Specifically, we will argue that employing ABA violates the principles of justice and nonmaleficence and, most critically, infringes on the autonomy of children and (when pushed aggressively) of parents as well.

<sup>&</sup>lt;sup>1</sup> We will mostly throughout this paper be using "identity-first" language that prioritizes "autistic individuals" over "individuals with ASD". However, we set up the problem here in terms of a "disorder", because it is a "disorder" whose "treatment" we will be arguing is unethical. See also n. 5.

<sup>&</sup>lt;sup>2</sup> Many would argue that much of the terminology (e.g., "treatment") surrounding discussions of autism is fraught with ableist assumptions that autistic self-advocates might be inclined to challenge (hence also the scare quotes in the title). However, for the sake of making our argument as broadly rhetorically acceptable as possible, we resist an inclination to the prolific use of square quotes from here onward and accept most of the vocabulary of the literature at face value.

<sup>&</sup>lt;sup>3</sup> We think it is crucial to take these voices from the autistic community seriously, rather than relying solely on researchers interested in purveying ABA. See the Autistic Self-Advocacy Network for a particularly strong statement on this point at <a href="https://autisticadvocacy.org/policy/briefs/interventions/">https://autisticadvocacy.org/policy/briefs/interventions/</a> One helpful reviewer also pointed us to strong statements from "Autistics for Autistics" (A4A) and Autistics United Canada ("Autistics United Canada").

<sup>&</sup>lt;sup>4</sup> We restrict our focus to treatment of children as the most common form of ABA (see n. 6). Our arguments could be made stronger for cases of making choices on behalf of older minors or adult wards. The case of consenting adults is an interesting issue we put to the side for this article.

<sup>&</sup>lt;sup>5</sup> The current best accepted practice is to use an identity-characterizing adjective rather than talk about autism as a condition people have. <a href="http://autisticadvocacy.org/about-asan/identity-first-language/">http://autisticadvocacy.org/about-asan/identity-first-language/</a> See also Kenny et al (2016).

<sup>&</sup>lt;sup>6</sup> Our argument will focus on the use of ABA as a treatment for children, which is its typical domain of application. Most patients undergoing the treatment range from three- to five-years-old (Kumak et al 2017). Our arguments are stronger the older the children are, but we will consider the implications of ABA as a treatment for younger patients as well.

There are several approaches one could take to this project. One could look at an analysis of ABA from the perspective of disability studies, and immediately note that it is problematic to "treat" patients for thinking differently (see Amundson 2000 for classic arguments of this form regarding disability generally). We think this isan important approach, but we do think that it is limited in effectively reaching as wide an audience as possible. We thus assume a more traditional bioethical framework that stays silent on the status of disabilities generally, and argue that even under these assumptions ABA should be problematic to the community at large. Furthermore, for purposes of this argument, we assume that ABA achieves its intended behavioral targets (see §1.3.1 below). We think this is probably correct (see Makrygianni et al 2018 for a defense of the claim that ABA successfully meets its behavioral goals); however, adjudicating that question—while still of vital importance—would involve a project more empirical than bioethical. We take one of the strengths of this paper to fill a void in the anti-ABA arguments from a more broadly accepted bioethical standpoint.

The question of the ethicality of ABA is of critical societal importance. As is common knowledge, ASD affects a large percentage of the population. In the United States in 2014 (the most recent year for which the Center for Disease Control has available data), 1 in 59 children was identified with ASD, up from 1 in 150 in 2000 (CDC 2018). ABA is often referred to as the "gold standard" of care for ASD (see e.g., "California Autism Center"), and is the officially (and glowingly) endorsed treatment of the operative document from the US Surgeon General (National Institute of Health 1999). If we are correct that the use of ABA at least frequently violates the standard principles of bioethics, then this has massive implications for healthcare and society generally.

Here is the overall structure of the argument. In §1.1, we introduce a (semi-)hypothetical autistic child. In §1.2 we will grant for the sake of argument that ASD is a disability, and even that it is a disability that can be circumscribed and individuated. In §1.3 we will give a description of ABA. In §2 we lay the groundwork for our ultimate argument, stressing that children have autonomy-related interests that are deserving of moral respect and consideration. §3 will put forward our central argument for the claim that treatment with ABA regularly violates the norms of medical ethics, which is that it inherently violates children's autonomy-related interests (and that as it is promoted it in practice is detrimental to parents' autonomy as well). As a framing device, we will take as given that gay conversion therapy is unethical, and argue that ABA is coercive in a remarkably similar way. In §4 and §5 we argue that in practice the employment of ABA also manifests a violation of justice and nonmaleficence (respectively). In §6 we look at objections, of which the most prominent is that ABA is ethical because "it works"; we will consider this as an argument from the bioethical principle of beneficence (that

<sup>&</sup>lt;sup>7</sup> Identified for example in Dawson 2019.

<sup>&</sup>lt;sup>8</sup> One might wonder if we are setting up a straw-man by citing (and proceeding to criticize) a twenty-year-old document. Unfortunately, it is the most current official government statement about the treatment of ASD. More relevantly, when one tries to track through the web of claims and citations supporting the use of ABA, one frequently ends up back at this twenty-year-old report.

<sup>&</sup>lt;sup>9</sup> The link between what we take to be an infringement on autistic rights and an infringement on queer rights is historical as well as conceptual—see an analysis of texts by Gibson & Douglas (2018).

everything should be done to benefit patients). We will also explore the reply that our argument proves too much, in that if valid it would demonstrate that any parenting behavior geared at altering the behavior of children was unethical. We discuss in §7 one exception to our general claim, and briefly conclude in §8.

Put briefly, the argument is that ABA is—among other things—an encroachment on the autonomy of children forced to receive it. Even granting that parents have the *authority* to decide in favor of ABA, doing so runs two very serious risks. First, it can alter children's identities by preventing them from forming and pursuing their own passions. Second—and more problematically—it can teach them that there is something wrong with who they are, and how to blend in rather than exercise their own unique capacities.

### §1.1 Patient X

There is a well-known saying in the autistic community that "if you know one person with autism, you know one person with autism." As such, focusing on any one case can miss the broader picture. We will discuss a hypothetical patient, whose profile was constructed from various case reports but predominantly from personal experience. Consider autistic Patient X. X has trouble with language, obsesses over the outcome of every professional wrestling match, and eventually stops going to school because it regularly causes sensory overload. As an example of sensory overload, group meals are terrifying, because he cannot filter different threads of conversation or overlook the sound of people chewing. Patient X also self-stimulates ("stims") by shaking his arms at many times throughout the day.

Clearly, one can sympathize with the parents' desire to ameliorate these symptoms. Just as clearly though, not *everything* that could conceivably help would thereby be morally acceptable—to take an extreme example, physically beating X out of his interest in wrestling would, pretheoretically, violate ethical norms.

Patient X exhibits at least four different kinds of "targets" that are regularly nominated as candidates for treatment—with one exception discussed below, these symptoms seem to cover all the *kinds* of issues that one might want to treat with ABA. However, we argue that for none of them is ABA an ethical treatment.

What are the four different kinds of behaviors X exhibits that could be the targets of interventions?

- 1) Stim Target—one could attempt to treat X's arm shaking.
- 2) Special Interest Target—one could attempt to treat X's special interests, for example by discouraging his watching professional wrestling.
- 3) Social Skill Target—one could attempt to target the suite of problems making it difficult for X to attend school.

<sup>&</sup>lt;sup>10</sup> See for example https://www.autismspeaks.org/sites/default/files/sctk\_about\_autism.pdf

<sup>&</sup>lt;sup>11</sup> Moreover, while there are many cases in the literature where we feel that ABA was not the appropriate treatment, we are reticent to cast judgment on real individuals' past parenting decisions.

4) Developmental Skill Target—one could attempt to target X's basic problems with language use.

In addition, there is one other potential target not present in X, but which can be found in people such as Patient Y. Y's ASD is comorbid with pica syndrome, which is a condition where she regularly tries to eat non-food-items.

5) Immediate Danger Target—one could attempt to treat a dangerous condition comorbid with ASD.

All of our arguments will address Targets (1) through (4). As a preview, we will claim that (1) through (3) pursue ethically questionable ends, and that using ABA for any of the first four employs ethically questionable means. We will return to discuss the Immediate Danger Target in §7.

#### §1.2 ASD as a Disability

For this paper, we will assume that ASD is a disability with individuation criteria that can roughly mark it off. If ASD is either not genuinely a condition (or one-dimensional spectrum) or is a condition but not a disability, <sup>12</sup> then the arguments we are about to make become that much easier. We do not and should not authorize—much less strongly encourage—parents to enroll their children in treatments intended to "cure" introversion. It would be ethically outrageous to force children into 25-40 hours of therapy for being too shy. To make our case against the ethics of ABA, we will assume the strongest possible opposition. We thus grant for the sake of argument that there is a one-dimensional autism spectrum, and that being on that spectrum genuinely does constitute a disability (in some sense) for one's life. Nevertheless, we argue, treating autists with ABA is unethical, and using various levers (discussed below) to compel parents to utilize ABA is also extremely problematic.

#### §1.3 Applied Behavior Analysis

What is Applied Behavior Analysis? According to the Association of Professional Behavior Analysts "The applied branch of [behavior analysis] (applied behavior analysis; ABA) involves using scientific principles and procedures discovered through basic and applied research to improve socially significant behavior to a meaningful degree." ("About Behavior Analysis") Our central argument will be that focusing only on patients' (and particularly children's) behaviors as are significant to society overruns their autonomy by encroaching on what is significant to *them*.

ABA is based on the science of operant conditioning ("What is reinforcement"). The central notion is that small behaviors that are rewarded (or punished) will be repeated (or inhibited), and that such small changes can eventually build to radically altered behavior patterns. The focus is exclusively on using incentives and disincentives to alter behavior, with

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<sup>&</sup>lt;sup>12</sup> For illustrations of this effect, see Douglas et al 2019.

the inner-workings of an individual treated as something of a black-box. While individual variants of ABA vary in how beholden they are to this behaviorist tradition, it is reasonably safe to say that operant conditioning and behaviorism are critical to ABA generally. The most well cited and respected form of ABA for autism (the "UCLA Model") typically involves 40 hours of therapy a week for two years (Herbert & Brandsma 2002). Given the potential heterogeneity of treatments under the "ABA" heading and the unregimented use of the term, we will focus on variants of the UCLA Model, though any methodology based in behaviorist principles would face similar concerns.<sup>13</sup>

Modern manuals (e.g., Cooper, Heron, & Heward 2007) often implicitly (and frequently even explicitly) trace their theoretical underpinnings to a 1968 article by Baer, Wolf, and Risley. Baer, Wolf, and Risley (helpfully) characterize the method of Applied Behavior Analysis by explicating all three words in its designation. Of the three, one ("analytic") will prove relatively unproblematic, one ("applied") will be disquieting in its original formulation but relatively adaptable to a modern medical context, whereas the third ("behavioral") will exhibit a fundamental feature of ABA whose ethical difficulties pervade modern practice.

The "analysis" component of ABA is simply the best scientific study of behavior. At times there seems something slightly sinister about even this element, as when the authors say that "an experimenter has achieved an analysis of a behavior when he can exercise control over it." (Baer, Wolf, & Risley 1968, 94) However, in reality the study of the causes of behavior is an entirely empirical question, and does not by itself have any normative value or disvalue. (That said, which behaviors one chooses to study is itself a thoroughly normative question—researchers do not tend to study why neurotypicals *don't* behave in certain ways.)<sup>15</sup>

Calling a therapy "applied" entails that it is designed to work in the real world, and whether it is efficacious depends on whether it achieves desired results of sufficient degree as to be useful. (96) One obvious area of concern turns on what it means to "work" and by whom a result be desired. Baer, Wolf, and Risley are explicit that the behaviors are for the "better state of

Since we are granting for the sake of argument that ABA is effective at doing *something*, technology, effectiveness, and generality do not impact our ethical analysis. Moreover, since the underlying principles to which they refer do not involve autonomy or bioethics, conceptual systematicity does not enter into our analysis either.

15 Thank you to an anonymous reviewer for pressing us on this.

<sup>13</sup> DIR/Floortime is a bit better (from our perspective), but there are similar costs: A summary at https://tinyurl.com/y2qnvk3s describes requiring "connection" via eyes as a goal and forcing extended conversation/manipulation based on child's wants (13). It's also extremely time consuming---4-8 sessions of 20 min each, plus 2-3 language sessions of 20 minutes, plus 2-4 20 minute motor/sensory sessions per day (see the structure/goals transcript *ibid*.). If we are correct that ABA is problematic, then the new movement of RDI—which trains parents in behavioral training (<a href="http://www.rdiconnect.com/">http://www.rdiconnect.com/</a>)—is doubly problematic., in both adhering to ABA principles and putting the parent in the role of enforcer rather than (or at least in addition to) supporter. (That said, one reviewer helpfully notes that parents have always been coopted into ABA enforces, so perhaps RDI is largely an old wine in a new bottle—see Douglas 2013.)

<sup>&</sup>lt;sup>14</sup> In addition to explicating the three words in the name, Baer, Wolf, and Risley also describe four other dimensions of ABA:

<sup>1) &</sup>quot;Technological"—that variables and responses be listed fairly systematically.

<sup>2) &</sup>quot;Conceptually systematic"—that ABA relate to more underlying basic principles.

<sup>3) &</sup>quot;Effective"—that the treatment make a big enough difference to be effective.

<sup>4) &</sup>quot;Generality"—more general outcomes are preferable, though there are probably limits.

society" (91) and what is "socially important" (*ibid.*). Making decisions for patients for the sake of bettering society seems immediately suspicious from a modern perspective (see §4), as doing so places comparatively little emphasis on good of the patients themselves. We do not argue that ABA practitioners are in practice motivated by anything other than a sincere desire to help individual patients, but we do argue that the theoretical foundations of the discipline do not provide an immediate guide to what constitutes providing such help. Presumably a more modern reading would require that the therapy be conducive to the well-being of the patient while respecting their rights, and so this is in principle fixable. However, when we examine how ABA is employed in practice (see especially §5), we will see that much of it at least appears to have inherited its foundations' interest in societal benefit at the expense of individual rights. <sup>16</sup>

Calling a therapy "behavioral" means that it involves what "subjects can be brought to do, rather than what they can be brought to say; unless, of course, a verbal response is the behavior of interest." (93) Note that while it *explicitly* discounts what patients say, the original work behind ABA literally did not even *consider* what patients thought. This was almost certainly due to their being beholden to Skinnerian behaviorism (they cite Skinner 1953). In §3 we will argue that therapy that merely modifies behavior while leaving the agent's underlying motivational structure intact is a violation of autonomy, in that it coerces people to act against their identity. On the other horn of the dilemma, replacing the requirement of mere behavioral change with a more thoroughgoing transformation only leads to a violation of autonomy of a different kind, in that it forcibly interferes with children's identity-formation process.

While we mostly have in mind the UCLA Model of ABA, for our purposes there are two problematic elements essential to any form of ABA. The first is its exclusive emphasis on behavioral modification in lieu of more holistic, humanistic, or cognitive interventions. An ABA intervention will be considered a success if and only if it results in a desired behavior, regardless of what is going on in the mental life of the child. The second feature that problematizes ABA is that this is done in a way that overrides the child's natural inclinations *and* does so via at least moderately coercive methods.<sup>17</sup> To paraphrase one person with whom we spoke, if "ABA" just involved giving praise when the child does something good, you would be able to forgo years of training in favor of a lesson that could fit on a greeting card. There might be someone somewhere who practices ABA using only positive words of encouragement, but this is simply not what past recipients of ABA have reported (Kupferstein 2018).

When looking at actual therapeutic practices, it is easy to overlook these aspects of ABA because many therapists (rightly) use a wide array of approaches. Some such therapies—for example cognitive behavioral therapy (Drahota et al 2011)—help the patient control their thought patterns (admittedly in addition to behavioral criteria). Our arguments against the

<sup>&</sup>lt;sup>16</sup> This is not to say that social good and individual good are necessary in tension. One could contend that a focus on societal norms still indirectly increases well-being by reducing clashes with society and increasing inclusion; however, as we will argue below (see §6.1 and §6.2), this by itself would not normally be taken to justify rights violations.

<sup>&</sup>lt;sup>17</sup> The guidelines from the Behavior Analyst Certification Board treat both "noncompliance" and stereotypy (i.e., stimming) as inherently problematic. http://www.bacb.com/wp-content/uploads/2017/09/ABA\_Guidelines\_for\_ASD.pdf

ethicality of ABA will not touch on these other methods, even though they are often practiced together.

What would ABA look like for patient X? It would typically involve 25-40 hours per week of intense one-on-one therapies. X would be rewarded for engaging in activities that make him more "normal". For example, X might receive food and treats for speaking clearly and sitting pleasantly at meals with other children or family members. There would also be efforts to wean X off of unapproved behaviors. X might have discomfort removed—for example by being given a drink of water to alleviate his thirst (Ryan 2013)—for focusing on activities other than professional wrestling, or for finding less distracting ways of calming himself down. There are two points we would like to flag about this treatment aside from the behaviorist aspects that will be our primary focus. The first is the sheer time and effort to do it well—every hour spent in ABA is an hour X cannot spend playing in an unstructured setting, being read to, etc. The second point is that in reality, ABA sometimes uses so-called "aversives" (see §5) i.e., punishment. Almost invariably (Anxious Advocate 2015)<sup>18</sup>, ABA uses some form of negative reinforcement, wherein a child's intense discomfort is only removed if they perform as they are instructed. Frequently this passes from negative reinforcement of positive behaviors to outright punishment for undesirable behaviors (such as stimming). Moreover, as one anonymous reviewer notes, even if only positive reinforcement is used, then withholding that reinforcement can itself be taken by the child as a form of harm. If we can make a case against ABA even when it does not involve action immediately harmful to the child, a fortiori ABA that involves aversives will be even more problematic.

# §1.3.1 The surgeon general's [warning]

Many proponents of ABA as a treatment for ASD cite its extensive support among policy makers, frequently citing that it has been endorsed by the United States Surgeon General (e.g., AutismSpeaks, California Autism Center). The report in question, issued in 1999, states that ABA has thirty years of research supporting it. One finds in the Surgeon General's Report a crystallization of the argument in favor of ABA—namely, that it is efficacious. For the purposes of this paper, we will mostly be granting the claim that ABA is efficacious—indeed, we argue that to a certain extent that is precisely the problem. If ABA were not efficaciously doing anything, the burdens it places on patients (25-40 hours a week, plus other issues to be discussed in §5) would obviously render it ethically odious. However, granting that it does *something*, we worry about what ABA is efficacious in doing.

Here is the definitive statement of ABA's success:

"Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. A well- designed study of a psychosocial intervention was carried out by Lovaas and colleague. Nineteen children with autism were treated

<sup>&</sup>lt;sup>18</sup> This post was written by a former ABA therapist, and contains useful links about ABA practice, as well as an extensive list of concerns regarding ABA that we do not have the space to address here.

intensively with behavior therapy for 2 years and compared with two control groups. Follow up of the experimental group in first grade, in late childhood, and in adolescence found that nearly half the experimental group but almost none of the children in the matched control group were able to participate in regular schooling. Up to this point, a number of other research groups have, provided at least a partial replication of the Lovaas model." (National Institute of Health 164, internal citations omitted)

Put charitably, the success of ABA was that it gave children the tools they needed to flourish in the environment in which they found themselves. Put uncharitably, thirty years of research validated the claim that with intense conditioning (40 hours a week, per the report) one can successfully get children to act *as if* they belong in a particular social construct.

# §1.4 On the Nature and Limits of Behaviorism

Given that our primary contention will be that focusing solely on socially acceptable behavioral outputs leads to ethical problems for ABA, it is worth first being a bit more precise about what behaviorism in general entails. Borrowing from Graham (2019), we can divide strict behaviorism into three compatible but distinct doctrines:

- 1) Methodological Behaviorism: Psychology is the study of behavior, not the mind.
- 2) Psychological Behaviorism: Behavior can be described entirely based on external factors, without reference to mental events or internal psychological processes.
- 3) Analytic Behaviorism: Claims about mental states are really just elliptical claims about behavioral input-output relations.

Remarkably, while behaviorism remains the foundation upon which treatment plans are built, it has (to our experience) largely been discarded in philosophical circles in favor of either (most commonly) the cognitive science of representations (Thagard 2018) or (less frequently) models of embodied cognition (e.g., Varela, Thompson, & Rosch 2019/1991). Among other reasons behind this trend, one dominant view is that specifically with regard to (at least) language use there is a general "poverty of the stimulus" (Chomsky 1959)—we simply aren't exposed to enough proper linguistic utterances to assemble language that is grammatical, productive (we can generate seemingly indefinite utterances), and systematic (we do not find children who understand "Mary loves John" but not "John loves Mary", despite having very different inputs and outputs).

For our purposes the important thing to note is that there is at least strong philosophical reason to suppose that, in addition to what people do, there is at least *prima facie* reason to suppose that it is important to take into account what people think and the perspective from which they view the world. However, as this is not necessarily the venue in which to settle long-standing metaphysical arguments, our ultimate contention (§3.2) will turn not on behaviorism's deficits as a foundational assumption from the perspective of theory of mind, but on its deficits as a foundational assumption from the perspective of modern bioethics.

In this paper, we will argue that autism advocates' rejection of ABA is bolstered by ABA's failure as an ethical treatment by contemporary standards. To illustrate this, we frame our

discussion using the four principles of bioethics, most commonly traced to Beauchamp and Childress (1979/2013). Our argument against the permissibility of ABA focuses predominantly on the specific way in which ABA undermines the principle of respect for autonomy. However, ABA should also be scrutinized on the basis of considerations of non-maleficence, beneficence, and justice. We will address how these issues manifest as they arise in the paper.

# §2 RESPECT FOR AUTONOMY IN AUTISTIC CHILDREN

We will argue that ABA is *pro tanto* unethical because it violates the autonomy of the children who are subject to it. We recognize that this argument will be controversial, not least because it is uncommon in the bioethical literature to treat respect for autonomy as a relevant moral consideration in decision-making on behalf of young children. However, we think this generally is an error, and an additional benefit of examining why ABA violates autonomy helps illustrate one reason why respect for autonomy is morally relevant when making decisions on behalf of even young children.

# §2.1 Respect for Autonomy vs. Respect for Decisional Authority

To begin, we will separate respect for autonomy from another moral consideration that is often conflated with respect for autonomy: respect for decisional authority. Decisional authority concerns who, in a decision-making context, is entitled to settle the question of how to act. One way of understanding the rejection of medical paternalism and the subsequent introduction of informed consent requirements in clinical decision-making, for example, is as a rejection of the claim that doctors are entitled to settle the question of how to proceed in treating a patient. Informed consent requirements are a mechanism for enforcing *patients* authority over medical decisions.

However, that an individual has decisional authority does not yet tell us *why* the individual has decisional authority. In determining where decisional authority ought to reside, we must offer justification for it residing with one party over another. And here, considerations of respect for autonomy often serve as the justification for awarding decisional authority to a patient. For example, perhaps patients are entitled to settle the question of how to proceed in the face of a diagnosis because treatment decisions concern a domain over which one is *sovereign* (Feinberg 1989). Or perhaps patients are entitled to settle the question of how to proceed in the face of a diagnosis because such decisions figure into the broader life-shaping activity that is constitutive of autonomous agency (Dworkin 1988). These are just examples of the way in which respect for autonomy can justify the allocation of decisional authority to patients with respect to medical decision-making. But respect for autonomy is not *equivalent* to respect for decisional authority.

Clarifying the distinction between respect for autonomy and respect for decisional authority is important for our argument, because the patients who are subject to ABA are often young children. Our argument is that ABA is *pro tanto* unethical *precisely because* it violates children's autonomy, so our argument would be in trouble were there no difference between autonomy and decisional authority.

Thankfully, there is no good reason to treat respect for autonomy as equivalent to respect for decisional authority. It has become increasingly common in medical ethics to think it may be appropriate to remove decisional authority *on the grounds* of promoting autonomy; for example,

when individuals threaten to make choices that will frustrate long-term goals (Levy 2011) or that seem to be unsupported by their beliefs about the world or desires (Quill & Brody 1996). Moreover, we may think there are cases in which, even if an individual does not have decisional authority due to general decisional incompetence, there are autonomy-based reasons to defer to certain preferences or to avoid interfering with them if unnecessary (Jaworska 1999). Autonomy interests extend beyond an interest in independent decision-making, and respect for autonomy should be attentive to these interests as they pertain to certain decisions, even if it does not make sense to award the individual the authority to settle the question.

We grant, therefore, that parents and medical professionals may have decisional authority when it comes to the question of whether ABA is appropriate. However, we reject any claim that considerations of respect for autonomy are irrelevant to determining whether ABA is morally permissible simply because the patient in question is not the appropriate bearer of decisional authority. Our argument, then, depends on showing that there are autonomy interests for young children, and that evaluating the permissibility of ABA requires attending to these considerations.

#### §2.2 Autonomy Interests and ABA

What autonomy interests of children need to be taken into consideration when deliberating on their behalf? There are two relevant interests that (A) young children can plausibly be said to possess, and (B) are relevant to determining whether ABA is morally permissible. These are: 1) an interest in freedom from interference with their ability to act on their desires, and 2) an interest in freedom to develop preferences that can be cultivated into more substantive passions or pursuits.

First, young children have an interest in not being subject to outside interference. Bullock and Lütkenhaus (1990) find that a majority of 23 month-olds exhibit signs of the "self as the subject of experience". As they point out, the "terrible 2s", wherein children are insistent on their demands and their desire to do things themselves, only make sense if they have a strong sense of their own desires and agency as opposed to others'.

But even if one is skeptical that children have a morally significant interest in enjoying non-interference with respect to present desires, allowing children *some* freedom from interference is an important part of developing future autonomy. Children who are regularly prevented from acting on their desires have a harder time developing the capacity to set goals and see them through, or to engage in longer-term planning activity (Feinberg 1992, Mullin 2007, Mullin 2014). Of course, a child's interest in non-interference is more readily defeasible than an adult's interest, but this does not imply that it is permissible to interfere with a child *whenever* the parent believes such interference will promote the child's well-being (Mullin 2014).

Second, young children have an autonomy interest in being free to choose and act in accord with their own preferences. Young children are capable, in some circumstances, of recognizing their own preferences, understanding how certain choices or actions may or may not align with these preferences, and acting on that basis. (Bou-Habib and Olsaretti 2015). Repacholi & Gopnik (1997) famously found that even 18-month-old children recognize when other people would prefer different things than they themselves would. Even though children's capacities for autonomous action are quite limited, it does not follow that there is *no* moral significance to the exercise of these limited capacities.

More importantly, however, children have an autonomy interest in being free to cultivate their own preferences into passions or pursuits; such activity is important to the process of *identity* formation. By allowing children the freedom to cultivate certain preferences or inclinations into deeper passions or pursuits, children begin the process of developing their identity. Alison Gopnik (2016) argues that good parenting is more akin to gardening than carpentry—the goal is not to produce a certain result, but merely to create the most hospitable possible conditions for howsoever the plant "chooses" to grow. Similarly, Mullin (2014) notes that parents should support children's autonomy by connecting certain actions or desires to outcomes or pursuits the child cares about, and being responsive to the child's interests as genuine reasons for action. Again, the requirement to refrain from meddling with the preferences of a child is weaker than a corresponding requirement for an adult; however, it does not follow that the child *has* no autonomy interest in developing and cultivating their own preferences.

Note that recognizing these autonomy interests does not require attributing to young children a particularly sophisticated degree of agency. Part of what renders these interests important is not just their connection to the actually existing degree of autonomous agency enjoyed by young children, but also their connection to a child's development into an autonomous agent. Moreover, nothing we have said thus far commits us to the claim that these interests function as *constraints* on medical decision-making. Rather, all we have argued is that there are autonomy interests that children have, and that these interests must not be disregarded when deliberating about whether ABA is morally permissible.

#### §3 ABA AND VIOLATING AUTONOMY

The identified autonomy interests are relevant because ABA targets the behavioral manifestations of certain preferences, passions, pursuits, or desires that young children may have, and it attempts to "correct" these behaviors. Insofar as children are prevented from acting on these desires or preferences, ABA disrespects children's autonomy interest in being free from interference in their preferences, their choices, and their actions. For example, if a child's fixation on the outcomes of professional wrestling matches is targeted by barring the child from watching professional wrestling or preventing the child from discussing professional wrestling, it is difficult to maintain that the child is being allowed to cultivate his passion.<sup>19</sup>

Our argument comes in the form of a dilemma. Assuming for the sake of argument that ABA is effective at changing people's behavior, it either does so via changing their underlying thought structures or values ("deep change"), or it does not ("superficial change"). If ABA is "successful" by way of deep change, then ABA violates autonomy insofar as it coercively closes off certain paths of *identity formation*. If ABA is "successful" by way of superficial change, then ABA violates autonomy by coercively modifying children's patterns of behavior to be misaligned with their preferences, passions, and pursuits. Such superficial change is a pervasive form of interference that compromises children's present and future autonomy.

Our main argument for the claim that both deep and superficial change are affronts to autonomy comes in the form of an analogy to "gay conversion therapy". We take "gay conversion therapy" to be a general term for any process by which a person or entity tries to change another's sexual orientation. This practice is now generally recognized as being ethically problematic. For example, in 2000 the American Psychiatric Association joined "the American

<sup>&</sup>lt;sup>19</sup> Some who have looked at Lovaas's work have made the stronger claim that at least in its original form ABA intended to frame desires directly. "If Lovaas's tenets are followed, childhood desire is readily remolded, and the reducation of deviant desires becomes a beneficent mission." (Gibson & Douglas 2018, p. 21)

Academy of Pediatrics, the American Medical Association, the American Psychological Association, The American Counseling Association, and the National Association of Social Workers" in condemning the practice, claiming that "the validity, efficacy and ethics of clinical attempts to change an individual's sexual orientation have been challenged." (American Psychiatric Association 2000) We argue that ABA should be challenged in almost precisely the same way.

# §3.1 ABA, Gay Conversion Therapy and Deep Change

Suppose, for the moment, that there were a pill one could give to a homosexual adolescent that would instantly make them heterosexual, and have no other adverse consequences. Would it be ethical to prescribe such a pill? We would argue it would not, as it would violate the patient's autonomy.

First, we should specify what we have in mind by "making the adolescent heterosexual". We do not mean that the adolescent will suddenly be compelled to act in ways consistent with opposite-sex attraction, despite retaining a disposition to be attracted to the same sex. Rather, we envision a pill that completely eradicates all dispositions or inclinations towards same-sex attraction, while giving rise to dispositions and inclinations towards opposite-sex attraction. Thus the hypothetical pill targets the emotional attachments, dispositions, and desires constitutive of sexual orientation, not merely the behaviors commonly associated with such attitudes and desires.

Administering such a pill, we argue, would violate the patient's autonomy because it eradicates dispositions, emotional attachments, and desires that are partly constitutive of the way one engages with and sees the world. Sexual orientation often affects our social interactions and relationships, the experiences to which we have epistemic access, and the activities we find enjoyable. The pill we have in mind destroys these dispositions, attachments, and desires. Moreover, it replaces these previous attitudes with an entirely different set of attitudes that inform our worldview and engagement. In other words, the pill coercively modifies the patient's *identity*.

There seems little doubt that both their claimed values and their very status as being on the Spectrum are central to autists' identities. This is why autistic self-advocates have been shifting towards referring to themselves as "autistics" or "autists" rather than "people with autism". Here is how it was put by the founder of Autism Network International:

I am not a "person with autism." I am an autistic person. Why does this distinction matter to me?

...Saying "person with autism" suggests that the autism can be separated from the person. But this is not the case. I can be separated from things that are not part of me, and I am still be the same person. I am usually a "person with a purple shirt," but I could also be a "person with a blue shirt" one day, and a "person with a yellow shirt" the next day, and I would still be the same person, because my clothing is not part of me. But autism is part of me. Autism is hard-wired into the ways my brain works. I am autistic because I cannot be separated from how my brain works. — Sinclair (2013)

<sup>&</sup>lt;sup>20</sup> Kenny et al (2016) find that among autists themselves (in the UK), "autistic person" is preferred to "person with autism". See also n. 5.

Note that it is not required for our argument that all autists identify with their "condition". If a significant number (and perhaps even a majority—see note 20) do so the inarguable presence of a stigma against being autistic, then a respect for autonomy would seem to demand that all should have at least the option of doing so. [58]

If ABA's successful "correction" of any of targets (1)-(4) occurs by way of eradicating and changing the underlying dispositions, attachments, and desires, then ABA coercively modifies the identities of autistic children much in the same way that the conversion pill modifies the identities of gay children. Hence ABA is a violation of the autonomy of autistic children in the same way that the conversion pill is a violation of the autonomy of gay children.

This argument invites three objections. First, one might argue that we have made an illegitimate shift in our understanding of autism's status. At the start of the paper, we stipulated that we would treat autism as a disability. However, in this argument, we seem to have proposed that autism is an identity. While it has become increasingly common to classify disability as a kind of identity, much in the same way that gender and sexual orientation are often recognized as a form of identity, this is a controversial claim that proponents of ABA will likely reject. So our argument sneaks in the back door the claim that one's disability is part of one's identity.

While our argument invokes a connection between autism and identity, it does not depend on the claim that autism *is* an identity, or that it is part of an identity. Rather, all our argument requires is the claim that autism is intimately *causally connected* to one's identity. Autism shapes how a person views the world, relates to others, experiences events and situations, and values certain pursuits over others. All of these are constitutive of one's identity. But it does not follow that we must be committed to the claim that autism itself is an identity. Thus we remain neutral on the question of whether disabilities are identities.

Second, one might argue that there is a disanalogy between the imagined conversion case and the ABA case. Specifically, the conversion case envisions an adolescent, while ABA generally concerns very young children. While it may be plausible that an adolescent has a secure identity that can be coercively modified, young children are just in the early stages of identity formation. And the coercive modification of these attitudes is not obviously a coercive modification of the child's identity. Thus, we have not yet shown that there is a genuine *autonomy* violation here.

We will grant that there is a difference in the degree to which we can expect an adolescent has developed their identity, and the degree to which we can expect a young child has developed their identity. However, it is wrong to assume that interfering with identity formation at a young age is always better than interfering with it later in life. Many professional dancers began dancing at age two, and they freely pursued it from that age on. Had a parent prevented them from continuing to pursue dance at that age and redirected them towards other activities, the parent would have interfered with a pursuit that has been central to their identity for the entirety of their lives. Second, even if there is not a settled identity being coercively modified, ABA interferes with the child's process of identity formation. By modifying the child's dispositions, attachments, and desires, ABA coercively *closes off* certain paths of identity formation. This undermines children's autonomy, and it fails to provide the kind of autonomy support necessary for good caregiving.

Third, one might point out that this argument depends on a conception of the self that radical behaviorism, and so ABA, simply does not recognize.<sup>21</sup> As Skinner states, "a person is

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<sup>&</sup>lt;sup>21</sup> Thank you to an anonymous reviewer for KIEJ for pressing us to address this.

not an originating agent; he is a locus, a point at which many genetic and environmental conditions come together in a joint effect." (Skinner 1974, 168). 'Identity' picks out only the unique constellation of genetic and environmental contingencies that cause the individual organism's behavior. However, our argument from deep change appears to rely on a picture of the individual as capable of free will, of being an "originating agent". Thus this argument sneaks in metaphysical commitments to free will that are unacceptable to the radical behaviorist.

However, the relevant conception of autonomy does not depend on the possession of free will. In the bioethics literature, personal autonomy generally refers to an individual's distinctive evaluative perspective, one that is the product of deliberation and endorsement or rejection of certain desires, pursuits, and commitments, and the capacities to choose and act in ways that align with this distinctive evaluative perspective (or to refrain from choosing and acting in ways that contradict this distinctive evaluative perspective). There is no reason to suppose that this requires an indeterministic worldview, barring a demonstration that compatibilist arguments are wholly unsuccessful.<sup>22</sup> Thus our argument that ABA violates children's autonomy because it coercively modifies the dispositions, desires, and preferences that underlie children's identities and shapes their process of identity formation does not depend on a commitment to free will.

# §3.2 ABA, Gay Conversion Therapy, and Superficial Change

Suppose, on the other hand, ABA does not really change the way a child thinks and perceives the world. Rather, it just changes the way a child behaves. Assuming the analogy holds in general, this would be akin to therapy that results in gay teenagers remaining gay but marrying partners of the opposite sex and starting a family. Here is where the analogy is most poignant, as we think almost everyone would grant that there is something fairly abhorrent in compelling people to live out their lives in ways that do not accord with how they really feel on the inside. This is true even if there would be large societal benefit to having a certain degree of uniformity; for example, even if we lived in a world where fear of gay people were used as a cudgel to push other regressive policies, we would not take that as especially good reason to force gay people into heterosexual relationships.

While there would obviously be a violation of justice (see §4) in forcing gay people into heterosexual relationships, it seems clear that the largest issue is a complete disregard for their autonomy. By conditioning individuals in such a way that their behaviors systematically misalign with their dispositions, attachments, and desires, we subject them to a particularly invasive, diachronic form of interference. We inculcate an inability to achieve an integrated self.

Note that on the superficial change argument, ABA must be evaluated not only in terms of its effects on the young child at the time of behavioral therapy; it must also be evaluated in terms of its effects on the child over their development into adulthood. If ABA is successful by way of superficial change, then ABA succeeds by systematically redirecting an individual away from their dispositions, attachments, and desires towards behaviors that oppose these attitudes. This is a clear violation of the child's autonomy-related interest in enjoying *some* degree of non-interference.

<sup>&</sup>lt;sup>22</sup> To explore this fully would take us beyond the scope of the paper. Berofsky (2005) argues that personal autonomy is compatible with a deterministic worldview.

While this argument applies clearly to the Stim Target, and Special Interest Target, one might hold out hope that the Social Skill Target and Developmental Skill Target are still reasonable to treat using ABA. Making Patient X stop stimming or give up his love of wrestling would subject Patient X to superficial change, causing X to act in a way dissonant from his own tendencies for the sake of ends that are not intrinsically valuable. But one might contend that there is surely nothing wrong with facilitating Patient X's ability to go to school, have group meals, or (especially) use language.

This is right, up to a point—going to school, enjoying group meals, and using language are reasonable (though not essential) goals to pursue; however, it does not follow from this that ABA is an ethically ideal way to pursue them. Recall that the central characteristic of ABA (or at least the UCLA Model) is to train patients to behave in certain ways. Traditional ABA would work by providing incentives for positive dinner behavior and/or aversive responses to poor behavior—as a self-identified behaviorist methodology, there is insufficient attention paid to the thoughts and feelings of the patients. Treatments that gave a patient like X coping skills (e.g., "take deep breaths to calm down when feeling overwhelmed") are undoubtedly good ideas. In practice many ABA therapists employ non-behaviorist techniques as well—however, the fact that ABA can be appended to more ethically sound procedures is no defense of ABA itself.

We take this horn to be the crux of our argument, for two reasons. The first reason is that the normative evaluation is more unavoidable. While there might be some who would argue that genuinely converting gay teenagers would not violate their autonomy since they would retroactively accept the change, we find it difficult to imagine the serious ethicist who would argue that gay people should simply be trained to act heterosexual.

The second reason that the challenge superficial change poses to autonomy is more serious than the challenge from deep change is that there is good reason to suspect that the change effected by ABA is in reality superficial. It is at this point that modern ABA research fails to divorce itself from its conceptual roots—invariably, the measures used to validate the treatment are behavioral measures. For example, Dawson and Burner (2011) laud the success of ABA at being enhancing cognitive abilities, language skills, social competence, aggressive behavior, and anxiety symptoms (617). Of those, only the last is any indication of deep change having been effected, and the finding was restricted to "high functioning" teenagers who underwent a form of cognitive behavioral therapy that was not even really an instance of ABA (the authors of the original study by White et al (2010) made only passing reference to ABA). The official statement of the American Academy of Pediatrics (Scott & Chris 2007, but reaffirmed as recently as 2014) in "Management of Children with Autism Spectrum Disorders" says that children who are treated with ABA have been "shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups." (1164) More recently, Linstead et al (2017) concern themselves exclusively with "skills". All of these measures are fairly typical of the autism literature. None of these is a measure of the child's actual identity, or even the child's actual well-being. We have seen no evidence that ABA effects deep change.

One might object that we have stacked the deck against ABA—given the nature of the scientific method, evidence for the successes of ABA will almost invariably be merely behavioral. There are two responses to this. First, now that children raised with ABA have grown

into articulate adults, we can also ask more directly what they think of ABA—by and large, the anecdotal evidence does not suggest deep change. As one example, ABA survivor Amy Sequenzia (2016) explicitly avers the analogy between ABA and gay conversion. While other autistic self-advocates do not always reveal to what treatments they themselves endured, many (e.g., Ne'eman 2010) disavow ABA from a seemingly personal perspective. Here is autistic self-advocate Max Sparrow (2016):

Similarly, if you train an Autistic to make eye contact and not flap their hands and say "I love you, too" and stay on task, it just makes them into an Autistic who can fake being not-autistic with some relative measure of success. Underneath the performance is still an Autistic brain and an Autistic nervous system and it is very important to remember that. Being trained to hide any reaction to painful noises, smells, lights, and feelings doesn't make the pain go away.

Second, one might have predicted that, if ABA really was only effecting superficial change, there would be evidence in the form of downstream adverse effects on its recipients. Tragically, such evidence is emerging. Children who received ABA self-report serious psychological problems (Kupferstein 2018), and there are recent data indicating a link between attempts to "camouflage" behavior in autists (what we would describe as engaging in superficial change) and suicidality (Cassidy et al 2018). (We will return to these results in §5.)

Third, one might object that once again, our argument relies on a conception of the self that is unacceptable to radical behaviorism.<sup>23</sup> The superficial change argument relies on the claim that there a person has a knowable set of mental states that are partly constitutive of the self, which can be alienated from behavior that is a product of genetic or environmental contingencies. But radical behaviorism denies that the self is anything *but* the collection of behaviors resulting from the unique set of genetic and environmental contingencies to which the individual is exposed (Skinner 1974, 168). Thus again, our argument from superficial change smuggles in assumptions about the self that are unacceptable on a behavioristic worldview.

We concede that the radical behaviorist is unlikely to find our arguments here compelling. However, we think that this objection reveals an interesting point about radical behaviorism and commitments of contemporary bioethics more generally. Radical behaviorism is capable of evaluating whether certain cases of modifying behaviors (and the attending feelings about behaviors) should be advised or encouraged. As Skinner notes, "We have no doubt made mistakes. We have discovered, perhaps too rapidly, more and more effective ways of controlling our world and we have not always used them wisely..." (Skinner 1974, 190). Yet such evaluation is consequentialist in nature: is the modification of an individual's behavior advantageous or disadvantageous? Have we made the individual better or worse off?<sup>24</sup> These questions approach something like a moral evaluation of certain applications of behavior-modification techniques.

What radical behaviorism cannot endorse, however, is the notion that a person has a distinctive evaluative perspective, deserving of its own moral considerability. (Silvers and

<sup>&</sup>lt;sup>23</sup> Thanks to an anonymous reviewer at KIEJ for pressing us to address this challenge from radical behaviorism.

<sup>&</sup>lt;sup>24</sup> Skinner understands 'advantage' and 'better off' in terms of survival. This in and of itself is at odds with contemporary understanding of well-being, but a radical behaviorist might be able to adopt a different conception of well-being. Therefore, our point here will not focus on the emphasis on survival being at odds with contemporary understandings of well-being in bioethics.

Francis 2009, 240). And sometimes a person's distinctive evaluative perspective might lead to choices and actions that diverge from what promotes that individual's well-being at a certain point in time. And in some cases, we are not permitted to prevent that individual from choosing in a way that aligns with their evaluative perspective, but that makes them worse off. This just is the principle of respect for autonomy in contemporary bioethics.

Such a picture is at odds with radical behaviorism. It does not make sense to discuss an *authentic* choice that is deserving of respect, independent of the predicted effects on the individual's well-being. On the radical behaviorist worldview, this picture simply attributes arbitrary moral significance to one set of genetic or environmental contingencies over another. In short, the radical behaviorist worldview has no room for the principle of respect for autonomy. Thus radical behaviorism is a worldview that deeply conflicts with contemporary bioethics, and specifically with the recognition of respect for autonomy.

## §3.3 ABA and Parents' Autonomy

Our argument that ABA violates autonomy has attended to the effects of ABA on the patient himself. However, there is some reason to be concerned that the continued assessment of ABA as an effective and ethical treatment threatens parents' autonomy as well. ABA is often presented to parents as the only method to deal with autism (Devita-Raeburn 2016), and is in many states the only treatment covered by state health insurance (*ibid*.), despite the availability of other therapeutic options such as occupational therapy (Schaaf et al 2014), cognitive behavioral therapy (Drahota et al 2011), mindfulness (Conner & White 2018), and sensory integration (Pfeiffer et al 2011). ABA is often pushed on parents by schools as well. The National Association of School Psychologists suggests 25 hours of ABA a week for autistic students, and parents have little or no leverage if they favor another form of treatment. Moreover, since Individualized Education Plans are often funded through Medicaid and since the government endorses ABA (see §1.3.1), schools often feel pressured to do so as well. The conjunction of these issues raises serious concerns regarding whether parents' decisions to have their children undergo ABA are truly voluntary.

To be clear, our argument is not that it is *always* wrong to pressure parents into a particular health decision—using coercive pressure to increase vaccination rates might for all we have said be completely reasonable. The claim is just that there should be a strong presumption against coercing parents' decisions, and that if the content of the decision is itself questionable, then pressuring parents into it only compounds those concerns. Thus the bigger issue is that, as discussed in §2.1, relocating the decisional authority from the children to the parents does nothing to diminish the fact that the child's *full* set of interests still must figure into the parents' and clinician's decision-making. Surrogate decision-makers cannot ethically simply disregard the autonomy-related interests the child possesses. Again, even if one were skeptical that the demand to respect a child's autonomy-related interests has the same moral weight as the demand

<sup>&</sup>lt;sup>25</sup> One anonymous reviewer helpfully notes that while CBT and OT are covered by insurance, they are *not* covered under mandated raises to service caps—in other words, it is open to insurance to cap the number of OT or CBT sessions at a potentially relatively low number.

to respect an adult's autonomy-related interests, it does not follow from such skepticism that there are *no* considerations of autonomy to be responsive to in surrogate decision-making. Thus a defense of the employment of ABA must demonstrate that its benefits outweigh the compromises to autonomy that are present, even if the demands of autonomy are weaker.

### §4 ABA AND JUSTICE

In general, an institution is unjust if (though not only if) it places disproportionate burdens on some sub-populations on the basis of morally irrelevant attributes. Being autistic is clearly not a moral failing. <sup>26</sup> Thus, if the practice and proliferation of ABA places a disproportionate burden on the autists themselves, there is reason to think it is unjust. We argue that it does so in two important respects.

The first respect in which ABA places an undue burden on autistic children is by defining therapeutic success primarily in terms of autists' ability to fit into normal societal structures. As already noted, the founding papers in support of ABA took ability to succeed in regular schooling as the ultimate measure of success (see §1.3.1). Goals have become somewhat more democratic since then, but it would be difficult to deny that the ultimate goal of ABA is to get autistic children to fit into society, without placing corresponding burdens on society to adapt to autists as they are.

However, perhaps a greater injustice is in simply treating ASD as something that merits elimination in the first place. Designating something as requiring a cure places an immediate social stigma on it, and this stigma has not been lost on the autists themselves. Ne'eman (2010) argues that any focus on eliminating autistic behavior is inherently problematic. This is true even if it is granted (as we did in §1) that ASD is a disability—it is not obvious that a condition being a disability implies that the condition should be "cured". Anita Silvers (2003) presses this point forcefully, arguing that "from the start, the conversation [should] take a neutral stance in regard to the intrinsic value of being disabled." (Silvers 2003, 475) To treat ASD as a condition to be cured would require a positive argument that ASD is not only a disability, but intrinsically disvaluable. If any disvalue of ASD stems from societal forces, placing the full burden of rectifying this situation on autists is unjust (barring an argument that society cannot bear some of the burden of change as well). For example, recent work suggests that even the social disinterestedness which is taken as a paradigmatic symptom of autism is partially a product of societal misinterpretation (Jaswal & Ahktar 2018).

One might wonder whether our argument here again depends on sneaking in a specific model of disability: the social model of disability.<sup>27</sup> On this account, disability is not just extrinsically disvaluable, but *merely* extrinsically disvaluable. Attempts to "cure" disabilities are inappropriate in part because they incorrectly assume that disabilities are intrinsically disvaluable states to be remedied. But if our goal is to make the case that ABA is ethically unjustifiable even

<sup>27</sup> Thank you to an anonymous reviewer for *KIEJ* for pushing us to clarify this.

<sup>&</sup>lt;sup>26</sup> We are not claiming that it is never *construed* as a moral failing, but rather that from an ethical perspective (and in particular from a bioethical perspective) simply being autistic does not actually violate operative moral norms.

granting our opponents the strongest assumptions possible, then endorsing a model of disability that presupposes that disabilities are merely extrinsically disvaluable weakens our argument.

As noted, we follow Silvers in thinking that we should not presume that disability is intrinsically disvaluable, nor presume it is merely extrinsically disvaluable. We treat it as an open question. But can we maintain that administering ABA to autistic persons is unjust while being agnostic about the intrinsic disvalue of ASD? Certainly. Even theorists who claim disability is intrinsically disvaluable will agree that it is also extrinsically disvaluable. Moreover, many of these theorists agree that social stigma, exclusion, inaccessibility (as well as negative psychosocial effects resulting from this social maltreatment) ought not be addressed by "fixing" the person so that they no longer suffer these bads. Insofar as the goal of ABA is to make the patient into someone more capable of functioning "normally" in social settings, ABA targets only extrinsic bads of ASD and attempts to resolve these bads by fixing the patient. This solution not <sup>28</sup> places the burdens of addressing these bads solely on the shoulders of autists; it also disregards the demand of autists to be free from stigma, exclusion, and inaccessibility as a claim of justice.

## §5 ABA AND NONMALEFICENCE

In this section, we argue that practicing ABA violates nonmaleficence in two ways.

The first way derives from the sheer costs of ABA. Whether one uses the 25 hours per week recommended by the National Association of School Psychologists or the 40 hours per week recommended by the original UCLA model, that is a large amount of time that cannot be devoted to other valuable activities. As Sparrow (2016) points out, most adults would have difficulty with this regimen and "[b]eing Autistic doesn't give a three-year-old child superpowers of endurance." This also assumes that the financial burdens of 25-40 hours/week of an ABA therapist do not adversely impact the child as well.

The second way is empirical, and has to do with how ABA is actually enacted in the real world. In practice, being the recipient of ABA is frequently an extremely negative experience. ABA frequently makes use of "aversives" (Devita-Raeburn 2016), wherein children are given negative consequences in response to engaging in problematic behaviors such as stimming or obsessing over special interests. Not surprisingly, exposure to such punishments can adversely impact children—otherwise they wouldn't be effective.

In fact, recent work suggests that exposure to ABA can have long-lasting effects on individuals. In a recent study, Kupferstein (2018) finds that children treated with ABA report significantly more Post-Traumatic Stress Symptoms (as defined by the DSM-5) than children who were not so treated. Anecdotal evidence from autistic self-advocates support the connection between ABA and trauma (e.g., Sparrow 2016). We would not want to argue that the study

<sup>&</sup>lt;sup>28</sup> Julian Savulescu appeals to this distinction to explain why parents morally ought not select away from skin color or biological sex, even if parents morally ought to select away from disability, when implanting embryos via IVF. Julian Savulescu, "Procreative Beneficence: Why We Should Select The Best Children", *Bioethics* 15(5/6) (2001): 423-424.

demonstrates that ABA really does tend to cause anything like Post-Traumatic Stress Disorder—the symptoms are self-reported, and the sample is (of necessity) non-random. However, the very fact that people who experienced ABA are disproportionately likely to *report* symptoms at the very least suggests the possibility of real harm as a result of the treatment.

Emerging data paint an even more stark picture, not about ABA itself, but about the results of autists' trying to diminish the symptoms of their autism to fit into social settings. Research by Cassidy et al (2018) finds a significant correlation between "camouflaging" behavior—autists trying to act in ways they perceive to be normal—and suicidality. Admittedly this is only of concern to ABA if it effects superficial rather than deep change—if it is really making people non-autistic, then there is no worry about camouflage. However, without knowing which sort of change is typical (and with strong suspicions that it's just the superficial variety), these results are extremely concerning.

Moreover, simply training a child not to act in a particular way can paper over the underlying cause of that behavior.<sup>29</sup> Here is one parent of an autistic child commenting on a school's attempt to manager her stimming:

The other thing that I noticed was that Evie would put her hand in her mouth and have it quickly removed by paraeducators and M. M said the reason was that it gets messy. I recognized that she did this when she was frustrated and that it was a coping mechanism. (Ryan 2013).

Obviously, overlooking the source of a patient's distress in favor of removing its visible manifestation is bad for the patient.

#### §6 OBJECTIONS AND REPLIES

In this section, we examine three objections to our claim that the use of ABA on children is ethically problematic, and the claim that coercing parents to employ ABA similarly problematic..

# §6.1 What of Beneficence?

Thus far, we have said that employing ABA typically violates three tenets of medical ethics—what of the fourth? Beneficence requires we do everything in our power to help patients, and many would argue that autists are clearly in need of help. Obviously, ASD is in many ways burdensome—ABA aims to alleviate those burdens by improving various behavioral metrics (IQ, language skills, etc.). Thus even if there are reasons not to employ ABA, there are equally strong (or stronger) reasons for doing so. Indeed, if one looks at any of the papers supporting ABA (for

<sup>&</sup>lt;sup>29</sup> We take as an assumption that behavior is not its own cause. We think there are good arguments for psychological causes independent of function (perhaps most famously Block 1981), but functionalists and even most radical behaviorists would acknowledge that there is more to human nature than a particular finite set of outputs. More importantly, as discussed in §3.2 bioethicists *must* think there is more to a person than behavioral outputs.

example the Surgeon General's Report), this is roughly the logic one finds (though not spelled out in bioethical terms)—we need to use ABA because it's been proven to help. However, in this section, we argue that it is at the very least unclear whether ABA is supported by beneficence either.

First, does ABA help the individual patient? The main point we would like to make in this section is that the goal of specific beneficence is to help individual people, which is undermined by making people into someone they're not. The gay conversion case is clear here—making a gay teenager who doesn't fit in into a heterosexual teenager who does might in some way create utility in the world in the form of one fewer stifled individual, but it does so by radically changing the teenager's identity. Thus we have not really helped this teenager, as he is. We have simply brought about a better state of affairs by changing him into a different kind of person, one who is more likely to be accepted by peers and society at large (see §3.2 on the need for a notion of identity in bioethics).

The problem is similar for ABA. Either the change ABA effects is very deep and transformative, or it is not. If it is transformative then we are not helping *this* child. Rather, we are improving the overall state of affairs by refashioning the child into someone more likely to integrate into current society. If it is not transformative, it would take much stronger evidence than currently available that the changes in behavior are actually conducive to well-being, given all we know about the dangers of altering overt behavior in ways that conflict with one's underlying identity. Even if one thinks that there are great benefits to be had by "passing" for normal, history has provided ample evidence that this is quite frequently not a good tradeoff.

One could, however, take a broader view of beneficence wherein our goal is not just to help people as they are, but to make better people. For example, Savulescu (2001) argues that, if given a choice, we should opt to have a child with better traits than a child with worse traits. He specifically cites the example of intelligence—given that ABA has been shown to increase IQ scores, doesn't this suggest that beneficence obliges us to engage in ABA?

However, even if it were overridingly important to select traits for children that give them the best quality of life, there is no reason to think the argument extends to ASD. As noted previously, the standard measures for autists' success make very little mention of the subjective well-being of autism. Perhaps Savulescu is right that we should select against a child with asthma, but asthma is a clear case of a disorder with neither a positive nor an identity-contributing component. Autism, by contrast, can help someone live a differently valuable life, and can be relevant to major components of that life's value.

The potential benefits to Developmental Skills are, we readily admit, the most compelling argument for ABA. However, we have two reservations about the benefits even in these cases. The first is that by simply training a child to talk or use the toilet, we are papering over whatever it was about their environment that inhibited them in the first place. *Something* is making the child act the way they are—perhaps this something can be adjusted by modifying downstream behavior, but there is no reason to think that this is necessarily the case. We are simply not in position to predict what sorts of physical or psychological consequences this might have down

the line. By contrast, engaging with a child to see what about the potty or language scares them would be unlikely to foster later problems. Second, upon close examination it turns out that many skills and delays that seem developmental can only really be assessed in a social context. For example, it is generally believed that many autists' difficulties with verbal communication requires serious intervention. We are suspicious of this use of ABA because it commonly turns out that "non-communicative" autists frequently communicate perfectly well—they merely communicate in ways to which people might not typically be sensitive. Dawson and Elder (2013) claim that this is universally true (or near enough):

Though every person with autism can learn to communicate, it's not always through spoken language. Nonverbal individuals with autism have much to contribute to society and can live fulfilling lives with the help of visual supports and assistive technologies.

Autism self-advocate Rosie King gives the example of her own siblings in her TED talk:

And one of the best things that I've achieved, that I consider to have achieved, is I've found ways of communicating with my little brother and sister, who as I've said are nonverbal. They can't speak. And people would often write off someone who's nonverbal, but that's silly, because my little brother and sister are the best siblings that you could ever hope for. They're just the best, and I love them so much and I care about them more than anything else.

Saying that King's siblings need to learn to talk is really just a declaration that we will not listen to the perfectly good ways they already communicate.

We admit that the proponent of ABA has a bit of room to maneuver here—*if* it could be argued that ABA would A) effect deep change rather than shallow change *and* B) make the child's life significantly better *and* C) not alter the child's fundamental identity in any morally pernicious way, *then* there might be a sense in which ABA helps the child. However—as we argued in §3—we think there is empirical evidence against (A), no empirical evidence in favor of (B) (see Silberman 2015 on some advantages of being autistic), and that (C) would not only be difficult to prove but stands in tension with (A). Thus, the claim that ABA satisfies beneficence is tentative at best. Given that it clearly violates the other three principles, the weight of reasons is in favor of it not being ethical.

## §6.1.1 Right to ABA

One might worry that a stronger case can be made for beneficence than we have presented. In fact, proponents of ABA often use the very language we employ to argue that not only is ABA permissible, but that it is actually a right of children to receive such treatment. One anonymous reviewer pointed us to a statement<sup>30</sup> of six rights that purports to show that children deserve effective ABA treatment. However, four of these "rights" only focus on children's

<sup>&</sup>lt;sup>30</sup> https://www.abainternational.org/about-us/policies-and-positions/right-to-effective-behavioral-treatment,-1989.aspx

entitlement to have ABA done *effectively*, and so do not really address our concerns that ABA's effectiveness could be precisely the problem. These four are the right to: 1) a good environment; 2) a competent analyst; 3) ongoing evaluation; and 4) research demonstrated to be "effective". If our concern is not with ABA being done well, but with ABA being done at all, none of these rights helps assuage that concern.

Two of the other "rights" might perhaps move in a more ethical direction. One right is that ABA increase independence. We acknowledge that independence is—all else equal—a good thing. However, given our nature as social animals generally it hardly seems like an overriding good. Most promisingly, the list of rights does say explicitly that the main goal should be the personal welfare of the patient. This is a step in the right direction, but it is somewhat vacuous without specifying what constitutes the patient's welfare. If "welfare" is defined in terms of conformity, then this right does not really make ABA any better. In fact, in this document it is defined explicitly in terms of "community standards", which is precisely what we argue should not be the metric of ethical treatment.

### §6.2 Good Parenting and Curing Laziness

One obvious concern with our argument is that it proves too much. Surely good parenting allows for—and indeed very frequently requires—changing one's child. Using ABA to improve one's child's life prospects is no different from using other motivational methods to improve their laziness. If the latter is ethically acceptable, then so must be the former. However, we would resist this analogy on two grounds.

The first disanalogy is that laziness is, on some accounts, itself a moral failing (one of seven "deadly" ones in fact), which ASD is not. It is generally acceptable to try to make one's children morally better people, but that does not by itself sanction any change whatsoever. It is probably good to be physically strong, but it is not immediately clear that parents should force weight-training regiments on their children.

In general, we should not want to do *everything* possible to assure our children easy lives—if it is harder to live as autistic or gay or black, then we would do well to focus our energies on eliminating the basis of that burden rather than in eliminating the underlying trait. By contrast, a world that expects children not to be lazy at least seems to be a relatively reasonable world.

Second, we note that even if ASD were analogous to laziness, the burden of ABA might well still be a bridge too far. 25-40 hours a week of therapy wherein we only remove extreme discomfort from the child when they exhibit non-lazy behavior would require extreme ethical justification.

Another way it could be argued that our argument proves too much is to note that many of our points about the ethics of changing who people are would apply not just to ABA, but to any treatment of ASD. This is actually a bullet we are willing to bite without too much hesitation. Analogously, while there are many serious costs to almost any particular method of gay conversion therapy, the more general harm is trying to treat therapeutically what shouldn't be treated in the first place.

That said, we are not *committed* to the conclusion that no treatments are ethically acceptable. Our central point in most of our arguments is that ABA alters behavior without engaging the patient as the person he is right now. Other therapies plausibly avoid this problem. For example, the cognitive behavioral therapy, occupational therapy, mindfulness, and sensory integration mentioned in §2.3 might provide coping skills that autists can use for their own internal well-being instead of merely training for a specific set of behaviors.

## §7 JUSTIFIED ABA?

We take the argument against using ABA to treat the General Identity Target, the Stim Target, and the Special Interest Target to be relatively decisive. Moreover, while it is generally laudable to improve social skills and life skills, ABA is not the way to do so—behaviorist interventions run afoul of autonomy (§3.2), justice (§4) and can have real negative consequences (§5).

However, what about the Immediate Danger Target? For example, pica syndrome, wherein children try to eat whatever they see, is a dangerous issue found more frequently in autistic children (Gillberg & Billstedt 2000). There is no way we could reconfigure society—no "reasonable accommodation" (Stramondo 2017)—that would prevent children with pica syndrome from regularly actively endangering themselves. As such, if ABA can be used to treat pica syndrome, beneficence would provide at least a *pro tanto* reason for doing so. The presumption should be against deploying ABA, unless there is strong reason to believe both that the behavior is significantly intrinsically harmful to the individual *and* that there is no other less disruptive method available. Even in this case, our previous arguments indicate that maximal care should be taken to target the intervention this specific problematic behavior, rather than all associated behaviors.

Crucially, using ABA to help mitigate the effects of pica syndrome is not equivalent to using it to affect autistic behavior, even if the latter correlate (or even cause) the former.

#### §8 CONCLUSION

In this paper, we have argued that autistic children should not be treated with (the dominant species of) ABA, as such treatment essentially violates their autonomy, and at least contingently does them direct harm and is unjust to one group of people. We have argued that the demand to help people does not make ABA obligatory, and so on balance it is to be avoided.

This paper suggests several avenues for further research. On the empirical end, it would be valuable to develop and implement new measures for the success of ABA that focus on individual well-being rather than particular markers of functionality within a given social structure. From a philosophical perspective, it would be good to get clearer on what makes certain aspects of someone's personality essential to them as selves versus being merely accidental. And from a social perspective, we would do well to structure our society in such a way that people who see the world differently can fit in without having to either change who they are or act like someone they're not.

Another avenue would be to more thoroughly integrate the present conversation with discussions of disability studies, which for the most part we have deliberately tabled for purposes of this paper. The literature on disabilities has valuable insights to offer independently of general bioethical considerations. For example, one reviewer noted that the very idea that we can divide people into those who need treatment and those who do not is based on a questionable dichotomy. Anita Silvers (2003) notes that all of us in our lives are sometimes providers and all of us our sometimes in need of help to achieve our goals.

On a personal note, we fully appreciate the temptation to attempt to "fix" one's autistic child. It can be difficult to watch adult autists who require custodial care in order to flourish, and think that is a life one wants for someone one loves. Conversely, there was no doubt a time it was difficult to watch discrimination against adult homosexuals and want that future for one's child either. In both cases though, we owe it to our children to accept them for who they are. If the right choice were always one we were naturally inclined to make, there wouldn't be much point to ethical analysis in the first place.

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