



For Whose Benefit?

Evidence, Ethics, and Effectiveness of Autism Interventions

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Executive Summary

As recognition and diagnosis of autism continues to increase, a variety of medical and social-behavioral therapies and services have emerged. However, little attention has been paid as to whether or not these services truly benefit autistic people. Autistic people are rarely involved in the creation or implementation of autism-related services, which creates questions around who is deciding what these services should address.

One of the main interventions for autism is Applied Behavioral Analysis (ABA). ABA is a model of intervention focused on changing the external behaviors of autistic children, with the goal of making an autistic child look and act non-autistic. Ethical concerns have been raised within the autistic community as to how ABA and similar practices serve to “normalize” autistic children, via teaching children to hide their autistic traits. Hiding autistic traits has been linked to worse mental health outcomes and increased suicidality in autistic adults. Furthermore, these practices often “normalize” autistic children at the expense of promoting key life skills, self-determination, and self-esteem. However, the autistic community’s concerns around therapies and services for autism go far beyond the issue of “normalization” or even ABA specifically.

In order to learn what specific concerns autistic people have with autism therapies and services, ASAN conducted a thorough literature search and review, focusing on what autistic people have said and written about autism services. We also conducted a literature search to explore the strength and quality of the evidence supporting different autism services.

In our report, we identify several main topics as critical to the evidence and ethics of autism therapies and services. First, we explore the strength of the evidence for different autism services, finding that it is often quite poor or that it does not support the grandiose claims that services often advertise themselves with. We also find that, even when there is evidence to support the efficacy of different interventions, it is rarely evidence of outcomes that are ethically sound and meaningful to autistic people ourselves. Next, we categorize the ethical concerns autistic people have with autism therapies and services broadly. In addition to the concerns around “normalization” raised earlier, we find significant concerns around violations of consent and bodily autonomy; the pathologization of unremarkable behavior; and the amount of risks interventions often subject autistic people to for little reward. We also find specific concerns around ABA, namely, the brutal practices that ABA historically and currently uses; ABA’s connections to LGBTQ+ conversion therapy; and the way ABA dehumanizes autistic people through its view of our behaviors.

We also address two common arguments around autism interventions: first, that “new ABA” is ethical because of its gentler approaches to “normalizing” autistic people when compared with “old ABA”; and second, that our concerns are solely with ABA and similar interventions. We argue that “new ABA” is no more acceptable or ethical than old ABA, even if it is less brutal. We then argue that our concerns are not with any single autism intervention or type of intervention. Rather, we argue that all autism services can have unethical components and that people developing, administering, or considering a therapy or service must analyze the ethics of said therapy or service closely.

Finally, we derive a core set of underlying ethical principles for autism-related services, and propose an ethics framework based upon these principles for the development and delivery of autism-related services for children, adolescents, and adults. We construct this framework broadly to address a wide range of current and future approaches, including applied behavioral analysis, developmental approaches, naturalistic developmental behavioral interventions, psychiatric medication, speech and language therapy, occupational therapy, and others.

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

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Context on the Evidence and Ethics of Autism Interventions

Introduction

As recognition and diagnosis of autism continues to increase, a variety of medical and social-behavioral therapies and services have emerged to address the needs of this population. However, little attention has been paid as to whether or not these services truly benefit autistic people. Autistic people are rarely involved in creation or implementation of autism-related services, which creates questions around who is deciding what autism services should address.

Extra attention has been paid to the idea of “early intervention”: the idea that getting services earlier can make a difference in how successful an autistic child will become. Early intervention is not in and of itself a bad thing; it is a federal program that funds multidisciplinary services for children with a wide range of developmental disabilities (*Early Intervention Program for Infants and Toddlers with Disabilities*, 2016). However, many people refer to “early intervention” to mean a specific kind of service called Applied Behavioral Analysis (ABA); early intervention based in ABA is often called Early Intensive Behavioral Intervention (EIBI). ABA is a model of intervention based in behaviorism, with the goal of making an autistic child look and act non-autistic. Ethical concerns have been raised within the autistic community as to how ABA and similar practices serve to “normalize” autistic children, rather than teaching any practical skills. Interventions such as ABA have the potential to cause physical and emotional harm to autistic people, a population that already experiences increased rates of abuse, neglect, and health difficulties. Increased consideration must be given to protecting the rights and welfare of autistic people experiencing autism services.

This paper will explore the ethical implications of autism therapies and services by documenting self-advocate perspectives on a range of different autism-related therapies and services, as well as perspectives on similar therapies from the broader disability community. From there, we will derive a core set of underlying principles, and propose an ethics framework for the development and delivery of autism-related services for children, adolescents, and adults. Such a framework will be constructed broadly to address a wide range of current and future approaches, including applied behavioral analysis, developmental approaches, naturalistic developmental behavioral interventions, psychiatric medication, speech and language therapy, occupational therapy, and others.

We recognize that large sections of this paper will focus primarily or exclusively on ABA. This is not *solely* a report on the evidentiary and ethical concerns associated with ABA. However, ABA is one of the most commonly used autism therapies. During our research, most of the literature we found and reviewed on autism services focused on ABA. We stress throughout this report that our qualms with ABA can potentially apply to virtually any therapy. We focus on ABA because it is one of the oldest autism services still in use, it is one of the most well-known and widely used autism services, it is one of the most heavily researched autism services, and it is one of the most widely critiqued autism services. Our larger goal with this report, however, is to detail our concerns with autism-focused therapies at large and provide suggestions on how to remedy those concerns.

A Note on Language

In this report, we use the terms “interventions,” “therapies,” “services,” and “supports” to refer to any program, medication, or procedure that purports to reduce autistic traits and/or help autistic people lead better lives. These four terms have roughly the same definition, but the connotations we associate with them are different. We use “therapies” and “services” as neutral and catch-all terms, especially when referring to a range of programs whose goals we may or may not agree with. We use “interventions” as to refer to therapies and services that see autism as something to be “intervened” upon and therefore target the reduction of autistic traits or otherwise pursue goals that are unethical or overall unhelpful to the autistic community. Finally, we use “supports” to refer to therapies and services that focus on enabling autistic people to lead self-determined lives and achieve meaningful individual goals.

History and Background on Autism Therapies

There is a substantial, complex history of therapies and services for autism. Applied Behavioral Analysis (ABA), one of the most common and prevalent types of interventions, largely dates back to O. Ivar Lovaas's work at UCLA in the 1970s (Devita-Raeburn, 2016; Silberman, 2015). Lovaas's work was based in behaviorism and relied on operant conditioning, or using external motivations to eliminate autistic behavior and make autistic children appear non-autistic. Much of the reinforcement used was aversive and violent: Lovaas himself talked about hitting, yelling at, and giving electric shocks to children who would not comply, stating that "you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense — they have hair, a nose and a mouth — but they are not people in the psychological sense" (Chance, 1974; Silberman, 2015). Although numerical data collection and documentation of specifically defined behaviors remains a core component of ABA, the field has shifted and grown in its interventions in the past decades. Other ABA interventions now include picture exchange communication system (PECS) and pivotal response therapy (Farrall, 2021; Sandbank et al., 2020; Stahmer et al., 2005). It is important to note that an intervention can have characteristics of ABA (such as using rewards and punishments to modify behavior) without being ABA itself.

Other autism-specific therapies and services have been developed, some as compliments to ABA and some as alternatives. These include Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), Sensory Integration Therapy, FloorTime, Pivotal Response Training, and Relationship Development Intervention Program (RDI) (Eikeseth & Klintwall, 2014, p. 2103). Sandbank et al. (2020), in their meta-analysis of existing autism therapies and services, categorize non-pharmacological therapies for young autistic children into seven categories: behavioral approaches, developmental approaches, naturalistic developmental behavioral interventions (NDBIs), TEACCH, sensory-based interventions, animal-assisted interventions, and technology-based interventions.

The history of pharmaceutical and medical intervention for autism is also complex, and in many cases, horrific. Until the mid-20th century, autism was often not distinguished from schizophrenia and other psychotic disorders; autistic children were in many cases diagnosed as "psychotic" or "schizophrenic" (Evans, 2014). Autistic people, along with other people with intellectual, developmental, and psychiatric disabilities, were confined in state schools, state hospitals, asylums, and other institutions and subjected to insulin shock, psychoanalysis, and drug therapies; none of which, of course, actually treated their autism. In the decades since, more and more autistic people have begun to live in the community instead of institutions. However, autistic people are still prescribed psychotropic medication, even if they have no co-occurring psychiatric diagnosis (Bershadsky & Giordano, 2013). There are currently two drugs approved by the US Food and Drug Administration for treating irritability in autism; both have substantial side effects (Coury et al., 2012; N. O. Davis & Kollins, 2012). Psychiatric drugs have also been prescribed off-label for repetitive and restricted behaviors in autism, although a meta-analysis found that there is little evidence for this use (LeClerc & Easley, 2015; Yu et al., 2020). Different autism- and I/DD-specific groups (like STOMP and APANA) as well as "sibling" movements like Mad Pride have campaigned against overprescription of psychotropic drugs (Branford et al., 2019b, 2019a; Murray, 2020).

Methods

In order to gather a range of perspectives and data related to the ethics and efficacy of different therapies and services, we utilized various search engines and scholarly databases to find different academic, governmental, and general audience materials related to the topics. We specifically looked for non-scholarly writing on the subjects by autistic people as well as scholarly writing and research that included at least one autistic author. We utilized the PubMed, Web of Science, and Academic Search Premier databases as well as the Google Scholar search engine. We created and maintained a list of key terms for each report and used the key terms during database searches. We also found a substantial number of relevant articles through citations in other literature, not database and web searches. For lay autistic perspectives, we relied largely on citations in non-scholarly writing, as well as several "masterposts" of writings about ethics in autism therapies and services by autistic people. From searching, we created a library of relevant materials using Zotero citation management software. We then sorted through the libraries and chose the materials most relevant to include in a literature review.

Due to this paper's reliance on the existing literature, we used a process to sort literature into categories of "relevant," "background," and "exclude." We defined "relevant" literature as central sources that either a) were written by a lay

autistic person on the ethics of different autism therapies and services, b) were scholarly articles that focused specifically on ethical concerns among autistic people about different therapies and services, or c) were meta-analyses on the effectiveness of different autism therapies. We defined “background” literature as literature that discussed therapies and services for autism more broadly or the general concept of ethics in disability but did not focus on ethics in autism therapies specifically. Finally, we excluded any literature that was not related to autism, autism therapies, or ethics in disability.

The State of the Evidence for Autism Therapies and Services

What Does the Evidence Say?

There is very little formalized academic research on various services and supports for autism, and what does exist tends to be low-quality and ethically dubious. Furthermore, the majority of this research focuses on whether or not an intervention, service, or support can be considered “evidence-based.” In many cases, the standard for an “evidence-based” service is altered when it comes to people with disabilities. Because of the medical model of disability,¹ priority is given to interventions that reduce or eliminate disability, rather than try to accommodate the needs of individuals. Thus, the potential harms of an intervention may be downplayed because the perceived rewards - a cure or reduction of disability - are seen as much greater through the lens of non-disabled researchers and providers.

Many aspects of being autistic are stigmatized within our society. Autism affects our whole lives, including the ways we process our thoughts, senses, movement, and communication. The way we interact with the world differs from non-autistic people, and with that comes pressure from society to conform to neurotypical norms.

This pressure extends to the kinds of therapies and services available to autistic people, as well as how “evidence” for successful therapies is interpreted. Rather than focusing on measuring aspects such as effective communication, daily living skills, and self-determination and self-advocacy, much of the “evidence” in autism intervention research is based on the goal of the subject of the intervention appearing less autistic. This is often referred to as becoming “indistinguishable from their peers.” Some of the parameters this framework measures do not translate to outcomes that would make the world easier to navigate for autistic people.

When therapies and intervention focus solely, or nearly exclusively, on making autistic people “indistinguishable from peers,” it is important to ask *why*. *Why* are autistic people the ones pressured, if not outright forced, to change behavior? *Why* are neurotypical people not pressured to be more inclusive of or open to autistic behavior?

When one looks at research on therapies and services, one should consider who decides what constitutes “evidence.” Autistic people have shared our experiences with various types of interventions, and proposed outcomes that could be measured that focus less on promoting neurotypical behavior. Ultimately, it should be up to people with disabilities to decide what success looks like for us, and have our priorities reflected in the creation and implementation of therapies and services.

Like any other studies of medical or therapeutic intervention, studies of therapies and services for autism should be held to high standards of data collection and analysis, as well as being clear where there are limitations or gaps in the data. Unfortunately, studies of different autism interventions often have serious methodological or analytical concerns that undermines the validity of their findings.

According to several different meta-analyses and systematic reviews of studies on the effectiveness of ABA programs, the overall evidence for the success of these programs is limited (Reichow et al., 2018; Rodgers et

¹ The medical model is one of many models, or ways of looking at, disability. The medical model positions disability as the result of an illness, condition, or trauma, and prioritizes prevention, treatment, and cure of disabilities. It is often contrasted with the social model, which focuses on the barriers disabled people face in society and prioritizes remedying barriers and providing accommodations (Griffen, 2016). Most disabled people’s actual experiences fall somewhere in between the extremes of these two models (i.e., most disabled people experience disability as partially stemming from a medical condition and partially stemming from social inaccessibility or barriers); however, autistic people generally tend towards a social model view of autism. There are more models of disability than just the medical and social models (Retief & Letšosa, 2018; Smeltzer, 2007).

al., 2021; Sandbank et al., 2020; Weitlauf et al., 2014). Although randomized controlled trials, where people are randomly assigned to either a treatment group (e.g., receiving ABA) or a control group (e.g., receiving no intervention), are considered the “gold standard” for assessing the effectiveness of interventions, few RCTs assessing the effectiveness of ABA exist. Project AIM, a meta-analysis on the effectiveness of different interventions for autistic children, found that only about 30% of the studies of behavioral interventions it examined were RCTs (Sandbank et al., 2020).

Much of the evidence for the effectiveness of ABA comes from single-subject studies, which only assess one child or learner at a time (Kohn, 2020). The obvious flaw in this is that the changes that a single child makes cannot be generalized to a broader population in the same way changes observed among a larger sample of children in a study can. Project AIM, and other meta-analyses of autism interventions conducted by the Cochrane Collaboration and the What Works Clearinghouse, discarded these studies entirely because of their lack of rigor and inability to be generalized to a larger population (*Lovaas Model of Applied Behavior Analysis*, 2010; Reichow et al., 2018; Sandbank et al., 2020). Similarly, a review of behavioral and developmental interventions for autism in the journal *Pediatrics* found only one “good quality” study among the 34 analyzed; the vast majority of studies were rated “poor quality” (Warren et al., 2011). Cochrane Collaboration reviews and What Works Clearinghouse reviews are considered to be high-quality authorities in which interventions are effective in the medical and education fields, respectively. Their inability to find more than five studies (Cochrane) or two studies (What Works Clearinghouse) that fit their criteria shows the lack of rigor among studies of behavioral interventions for autism.

Furthermore, rigorous studies of behavioral interventions for autism often do not show significant effects among people subjected to the interventions and many studies of behavioral interventions do not follow up with participants for more than two years after the intervention has concluded (Rodgers et al., 2021). A Department of Defense report to Congress on the Autism Care Demonstration, which covers ABA services for military dependents, found that “approximately 76 percent of beneficiaries made little to no change in their symptom presentation after 1 year of ABA services” (*The Department of Defense Comprehensive Autism Care Demonstration Quarterly Report to Congress, Second Quarter, Fiscal Year 2019*, 2019). Furthermore, as Sandoval-Norton et al. demonstrate (2021; 2019), the evidence is particularly lacking for ABA’s effectiveness for non-speaking autistic people and autistic people with intellectual disabilities, despite non-speaking people and autistic people with intellectual disabilities being subjected to ABA at a higher rate than speaking autistic people without intellectual disabilities.

Although the majority of research into the effectiveness of autism therapies and services focuses on ABA and similar behavioral interventions, other autism-specific therapies show a similar lack of evidence (Hughes, 2011). Systematic reviews into behavioral interventions, developmental interventions, and sensory interventions found that even when studies showed positive results, the strength of the evidence supporting these results tended to be weak (Warren et al., 2011; Weitlauf et al., 2014, 2017). Project AIM also found limited evidence for most of the types of autism interventions they studied, especially when they limited evidence to only RCTs (Sandbank et al., 2020). Several analyses of social skills interventions found that the effectiveness of these interventions is small to moderate at best and the evidence base supporting these interventions is incomplete (Bellini et al., 2007; Davenport et al., 2018; McMahon et al., 2013; Williams White et al., 2007).

Research into pharmaceutical interventions (i.e., prescription drugs) for autism have also been mixed in their outcomes. A 2017 analysis of pharmaceutical interventions for autistic children found that the strength of the evidence, or how confident the researchers were in their results, was low, despite randomized trials (Williamson et al., 2017). Moreover, the researchers found that of the drugs that did show some effectiveness, many had significant side effects, including weight gain, appetite and behavior changes, and movement disorders. Other meta-analyses of pharmaceutical interventions for autism have found similar results: the drugs with the strongest evidence also had significant side effects and drugs with lesser side effects do not have strong evidence supporting their use (Fung et al., 2016; Masi et al., 2017).

Conflicts of interest – when the people running a study may benefit from the study showing certain results – are present but undeclared in many studies of autism therapies and services (Bottema-Beutel et al., 2021).

These studies are often run by researchers who are also the ones delivering the intervention or have a financial stake in the intervention succeeding. Two different studies found that conflicts of interest are present in a majority of autism intervention studies but only fully disclosed in a fraction thereof: the first, examining studies of early interventions for autism found that 70% of studies had conflicts of interest but only about 6% fully disclosed them (Bottema-Beutel et al., 2021). The second, looking specifically at studies of ABA interventions, found that 84% of the studies had conflicts of interest but only 2% fully disclosed them (Bottema-Beutel & Crowley, 2021).

While there are some scholarly investigations and essays that examine autistic perspectives on autism interventions,² the vast majority of exploration into any autism intervention does not inquire into the effects of the intervention onto the mental well-being or overall experience of the autistic people under study. There is, moreover, a lack of qualitative exploration into autistic perspectives on different therapies and services, including perspectives from autistic people subjected to various therapies and services. The vast majority of scholarly research on autism therapies and services is quantitative, using measurements that were not developed in conjunction with autistic people, and does not inquire into how the autistic people subjected to the intervention feel about the intervention. There is an overwhelming amount of non-scholarly writing by autistic people, our family members, and former intervention practitioners on the harms unethical or simply unhelpful interventions cause. However, to date, there has been little, if any, scholarly analysis of this writing or even scholarly citation of this writing. Autistic people, especially multiply marginalized autistic people, are already kept out of academia through a mixture of explicit and hidden tactics. It is disappointing, though not surprising, that our writing is also barely considered worthy of scholarly inquiry.

Although the side effects and potential harms of pharmaceutical interventions are meticulously documented within autism research, the same cannot be said for non-pharmaceutical interventions. Bottema-Beutel et al., in their study investigating adverse event reporting in studies of interventions for autistic children, found that of 150 studies examined, only 11 mentioned adverse effects at all, and of those, only four reported adverse effects or adverse events from the study. To be clear, this was not because none of the other studies had potential adverse effects – the research team found that at least 20 studies reported reasons for participant withdrawal that could be adverse effects or events (2021). A similar study by Papaioannou et al., which, although not autism-specific, examined unreported adverse events in behavioral and psychological interventions, found that adverse event reporting varies heavily between studies and often uses inappropriate measures (e.g., those developed for pharmaceutical interventions) (2021). These findings mirror the vast amounts of anecdotal and non-scholarly evidence from autistic people and our allies documenting the potential harms of a wide array of non-pharmaceutical interventions. Just because an intervention does not have a pharmaceutical or explicitly medical component does not mean it is free of potential harms. Given that non-pharmaceutical interventions are often the first, if not the only, types of interventions autistic people experience, and the voracity with which these interventions are pushed on autistic people and our caregivers, it is dangerously negligent that there are not better standards for reporting adverse events from these interventions.

Furthermore, it is important to assess whether a measurement can and is actually collecting data on the domain it seeks to collect data on. A study that judges autistic mental health, for example, by measuring the number of meltdowns someone has in a given week, is not necessarily measuring what it claims to measure. Autistic meltdowns happen because of a wide array of internal and external factors; they cannot be directly linked to mental health. A reduction in “autistic traits,” moreover, may come at the expense of mental health: masking or camouflaging autistic traits has been linked to worse mental health in autistic adults (Cage et al., 2018; Cassidy et al., 2020).

Qualitative studies of, alongside both scholarly and non-scholarly writing from, autistic people who have undergone ABA are often dismissed as “just anecdotes” or “not rigorous enough” to count. This is especially the case when these studies and writing oppose ABA or other autism interventions. This ignores that many of these qualitative studies are conducted using rigorous, externally validated methods for both data collection and analysis.

Numbers and quantitative analysis cannot tell the full story of any autism intervention. There is no way, using purely quantitative methods, to show the full effect, good or bad, of an intervention on autistic people’s mental well-being, whether or not autistic people actually *like* the intervention, and whether or not autistic people actually find the

² See, for example: (Chapman & Bovell, 2020; Freitas, 2020; Gibson & Douglas, 2018; Kirkham, 2017; Leadbitter et al., 2021; McGill & Robinson, 2020; Milton, 2014; Ne’eman, 2010; Sandoval-Norton & Shkedy, 2019)

intervention meaningful and relevant to our lives and goals. Therapies and services are not merely about whether someone improves a specific skill or decreases a certain behavior. Therapies and services are part of autistic people's lives and therefore things that we have thoughts and feelings on. Autistic people's quality of life, like anyone else's quality of life, is more complex than simply a tally of skills and behaviors. Quantitative analysis-only studies and reports largely ignore this because of the difficulty of measuring subjective experiences with qualitative measures.

This, combined with the lack of high-quality quantitative evidence from RCTs and meta-analyses for many types of therapies and services, should be enough to cast doubt on whether it is truly ethical – let alone effective – to subject autistic people, and particularly autistic children, to them.

Evidence of What, Exactly?

The data are clear that many therapies and services for autism are nowhere near as “evidence-based” as they claim to be, but the question remains: even if these therapies and services had strong, rigorous evidence that they worked, what would they be working to do? The earliest ABA practice – that of Lovaas and his students – had a clearly stated goal of indistinguishability, or making autistic children appear just like their non-autistic peers. Since then, interventions may focus on “reducing” autistic traits, such as stimming or echolalia, or “promoting” non-autistic ones, such as eye contact or typical spoken language. Other interventions may focus on changes in IQ scores, or whether or not someone has learned a specific “skill.” These intervention outcomes measures are often intangible, non-specific measures that do not translate into useful everyday gains or a better quality of life for the autistic person. Shona Davison, an autistic educator and mother to autistic children, summarizes this in three questions: “Perhaps we should be asking: ‘should we change the behaviour?’; ‘who will benefit from changing this behaviour?’; and ‘are we changing behaviour without addressing an underlying root cause?’” (Davison, 2018).

The behaviors ABA and other unethical therapies often target for reduction and eradication are furthermore often forms of communication, particularly in non-speaking autistic people who have no consistent access to other forms of robust communication. An autistic person who cries and hits their head repeatedly may be trying to express internal pain or discomfort; even if this is not the case, the person still deserves compassion and inquiry into why they are doing this, rather than compliance training to reduce the behavior. So-called “challenging behavior” may be a sign that something is wrong, such as a medical issue or the person being abused (Kripke, 2016b). If a therapy is “effective” at silencing this behavior without giving the person another (hopefully more effective) way to communicate what they are trying to say or meet their needs, it is effectively silencing that person's ability to communicate or receive care at all. Behavior may also be a way to communicate emotional or mental distress or sensory overload.

Moreover, many of the behaviors targeted by ABA, such as making eye contact and reducing stimming, among autistic people are merely the result of differences between autistic and non-autistic communication and world views. Damian Milton, an autistic sociologist, terms this the “double empathy problem,” which he defines as “when people with very different experiences of the world interact with one another, they will struggle to empathise with each other” (2018b). In other words, communication and empathy breakdowns between non-autistic and autistic people are not solely the fault of the autistic person or their autism – they are the result of two people with significantly different backgrounds interacting without understanding each other. The answer lies not in pathologizing and eliminating the autistic person's behavior but for both people to understand each other's background and needs in an interaction.

There is also substantial emerging research showing that autistic and non-autistic people have different communication styles and that this may be the cause behind many of the communication breakdowns between the two groups, not communication or social deficits on the part of autistic people (Crompton, Hallett, et al., 2020; Crompton, Ropar, et al., 2020; R. Davis & Crompton, 2021; Heasman & Gillespie, 2019). Said research also shows that non-autistic people's judgements of autistic people also plays a role in hindering autistic-non-autistic communication (Alkhaldi et al., 2019; R. Davis & Crompton, 2021; Edey et al., 2016; Heasman & Gillespie, 2018; Sasson et al., 2017; Sheppard et al., 2016). This research has important implications for service and intervention provision – namely, that even if interventions to “normalize” autistic people worked, they still would not fix differences in communication styles.

The question of “evidence of what?” also applies to pharmaceutical interventions. Although some medications have shown effectiveness in reducing aggression and hyperactivity in autistic children (LeClerc & Easley, 2015), eliminating

or reducing such behaviors on their own is not acceptable. As we have previously discussed, behavior can be a form of communication and autistic people (like all people) who “act out” or act aggressively may have unmet needs. Studies showing efficacy of medications in reducing aggression or hyperactivity largely do not seek to answer the question of *what* is causing the aggression or hyperactivity in the first place. Moreover, it bears examination whether these pharmaceuticals are actually addressing core autistic traits or whether they are addressing co-occurring conditions. Autism and ADHD can be and are co-occurring as can autism and anxiety disorders. In both these cases, pharmaceutical interventions may help someone to control symptoms of ADHD and/or anxiety. In turn, the person’s autistic traits when they are in distress (e.g., meltdowns, sensory overload) might lessen because they are in less overall distress all the time – but that does not mean pharmaceutical interventions directly lessen the traits of autism, not that should an outcome would align with the autistic community’s interests.

If the argument is then that an intervention is worth it, despite the risks and ethical pitfalls, because of scientific evidence, it is worth considering: whose evidence? Michelle Dawson, an autistic autism researcher, writes in her critical essay “The Misbehaviour of Behaviourists,” “Societal and scientific assumptions about what constitutes freedom and integrity for disabled people have often been wrong. There exists no reason to believe that our society and its scientists are uniquely immune to these defects” (2004).

Furthermore, as Ne’eman (2021) explains, using decreased autistic traits as a measure of success is unethical. Even if a quantitative measure has been created, tested, and externally validated, Ne’eman writes, “Measures are not neutral, however. They carry their creators’ value judgments” (2021, p. 569). The choice of measurements – almost always made by non-autistic people – as to what constitutes “improvements” in an autistic person undergoing an intervention is not a morally neutral one. Deciding that a reduction in harmless but visibly autistic behavior (e.g., stimming, lack of eye contact) is an “improvement” does nothing to teach autistic people useful skills or coping mechanisms for dealing with issues like sensory overload. It merely teaches us that our natural ways of existing are to be suppressed or eliminated if we are to “improve.” These “passing demands,” as Ne’eman calls them, are neither effective nor ethical ways of helping autistic people lead overall better lives.

Autistic people, particularly multiply marginalized autistic people, have had far less input into what constitutes good or ethical research or practice in autism interventions. Given this fact – that these interventions often have little, if any, input from the people they seek to help – Dawson’s statement becomes even more relevant. Studies may show that an intervention improves language, IQ, or adaptive skills among autistic people – but unless those were the goals of the autistic people in the intervention, the intervention was at best misguided.

There is also substantial research highlighting the need for more autistic involvement in autism research (Cascio et al., 2020, 2021; Chown, 2019; den Houting et al., 2021; Milton et al., 2014; Pellicano & Stears, 2011). Cascio et al., moreover, write that “exclusion of marginalized subgroups of people with autism is a major ethical concern,” and that future research must include a more representative sample of autistic people, including autistic people of different races, genders, ages, languages, support need levels, and communication styles (2021, p. 1). Projects such as the Academic Autistic Spectrum Partnership In Research and Education (AASPIRE) work to increase the amount of autistic participation in designing and carrying out autism research through the use of a Community Based Participatory Research (CBPR) approach (AASPIRE, 2020a).³ However, the vast majority of autism research does not use a CBPR framework or include autistic people as meaningful members of the research team.

Clearly, effectiveness is not the sole measure of whether a therapy or service is ethical or appropriate. Therapies and services must also focus on what constitutes a successful outcome *to the autistic person*. Non-specific outcomes – especially standardized outcomes that implicitly or explicitly use indistinguishability as a benchmark – may give the impression that an autistic person is making progress in an intervention while obscuring the fact that the intervention does not target skills or issues that the person themselves values. Or, conversely, these non-specific outcomes may give the impression a person is making little or no progress in an intervention because the outcomes do not and cannot measure the progress that a person is actually making. Moreover, even if an intervention is targeting the skills and issues

³ CBPR, according to AASPIRE, is “an approach to scientific inquiry in which scientific professionals and members of a specific community work together as equal partners to develop, implement, and disseminate research. As a form of action research, CBPR projects aim to make changes in the world that are desired by the community. In a CBPR project, the lived experience of community members and the academic learning of scientific professionals are valued as equally powerful sources of knowledge. Community-academic partners are expected to learn from each other and respect each others’ expertise” (AASPIRE, 2020b)

the autistic person wants, that is not a guarantee that its practices are ethical or humane, as we will discuss in the next section.

The Ethics (or Lack Thereof) of Autism Interventions

We have discussed a number of evidence issues surrounding autism interventions. We consider all of these ethical issues, because we believe it is unethical to subject someone to an intervention with a shoddy evidence base. However, there are further ethical issues. We begin first with a section on ethical concerns among all autism services, including consent violations and the removal of autonomy, the pathologizing of unremarkable behavior, and how the risks of too many autism interventions outweigh the rewards. We then move into a section discussing ethical concerns with ABA specifically: its torturous roots and current realities, its connections to conversion therapy, and the way it dehumanize autistic people.

General Concerns in Autism Interventions

“You don’t own your own body”: Consent Violations and Removal of Autonomy

A hallmark of unethical therapies is the lack of respect for a participant’s “no” or refusal to do something. ASAN’s interviews with autistic people who had undergone various behavioral interventions, found that “[participants] placed a high value on consent and respecting the autonomy of autistic people and other people with disabilities” (2017, p. 2). Yet multiple participants also noted that they had been subjected to therapies where they were forced (sometimes physically) to comply. One participant stated that such treatments “teach you to anticipate that when you say ‘no,’ they’ll bulldoze through that because you don’t own your own body” (2017, p. 2). Similarly, a former ABA practitioner, writing about their experiences, states that children they worked with learned, implicitly or explicitly, “People with more power than me can force me to do whatever they want ... Nobody, not even my parents will come to my defense ... Other people are in charge of my body ... I’m not allowed to say no, or protest ... It’s OK for people to physically move me if I’m not doing what they want me to do” (birdmadgrll, 2017).

Frameworks that require the autistic person to comply or surrender bodily autonomy or frameworks that position non-compliance as something to be eliminated are unethical and abusive. People with intellectual and developmental disabilities, including autistic people, are far more likely to be abused or be the victims of crime than non-disabled people (Child et al., 2011; Friedlander, 2017; Harrell, 2017; The Arc’s National Center on Criminal Justice and Disability (NCCJD), 2015; “The Sexual Assault Epidemic No One Talks About,” 2018). Educators, parents, therapists, and anyone else who works with disabled people, especially disabled children, know how serious an issue abuse is and have a duty to prevent it. Compliance-based interventions teach “autistic [people] that they cannot act on instinct, but must obey the nice authority voice” (Michael, 2018); something that is antithetical to developing personal safety and self-advocacy skills. Non-compliance – and the ability to evaluate situations and decide when it is safer to refuse to comply – is a fundamental life skill. The same behaviors that are encouraged in non-autistic children as safety mechanisms or “stranger danger” (e.g., telling someone “no” loudly, running away from someone who makes you uncomfortable) are pathologized as “non-compliance” and “elopement” in autistic children. Such pathologization only teaches autistic people that our “no” is meaningless and that our bodies are not our own.

A common technique in various autism therapies is hand-over-hand instruction, where the interventionist places their hand over the autistic person’s hand to guide or prompt them into completing a task. The problems with hand-over-hand instruction are well-documented. It increases prompt dependency – the likelihood that the autistic person will not be able to begin an activity at all without a prompt or command, even after they are no longer in the intervention (Ahern, 2016; Enders, 2016; Sandoval-Norton & Shkedy, 2019). More important, however, is how hand-over-hand techniques reduce or fully remove someone’s ability to voluntarily move their body as they like (Sedgwick, 2019). It is effectively telling the autistic person that they do not have the ability to say or gesture “no” and that they will be forced to comply, no matter what.

The goal of ethical interventions is developing skills, autonomy, and self-determination, not teaching and enforcing compliance. It goes without saying that autistic people have as much right to control and be secure in our own bodies as our non-autistic peers do.

Pathologizing Unremarkable Behavior

When examining the ethics of any given intervention, it is important to ask: would the behavior this intervention seeks to correct be cause for concern in a non-autistic or non-disabled person to the point where it would require significant, specialized intervention? A person being autistic should not make every single thing they do a potential target for autism intervention.

Autistic people, being people, have a wide range of emotions, preferences, and behaviors, just like non-autistic people do. But the same behaviors in autistic and non-autistic people are treated quite differently. An autistic child might be punished or deemed aberrant for the same range of behaviors that non-autistic children engage in all the time: playing a harmless prank on someone, fidgeting in their seat, or making jokes with a friend (Forest Vivian, 2018). Similarly, non-autistic people are often allowed to be upset or express discomfort with something someone else does to them without being labeled “non-compliant” or having “behavioral disabilities” (Fiore, 2017).

The behaviors targeted by unethical therapies are often harmless and self-regulatory or self-soothing. There is a link between hiding (masking/camouflaging) autistic traits, such as stimming, and increased depression and suicidality (Cage et al., 2018; Cassidy et al., 2020). Stimming, for many autistic people, is essential for our own self-regulation. It is often involuntary, meaning that we have little to no conscious control over it. Yet therapies still target it for extinction in a futile attempt to make autistic people appear more “normal,” even if everybody, including non-autistic people, stims. To go back to Davison’s question of “who will benefit from changing this behaviour?”, the answer here may be less “the autistic person themselves” and more “people around the autistic person who are worried about how they look.”

It is also unethical to apply exaggerated or hyperbolic labels of “challenging behavior,” “self-injury,” “inhibiting learning,” and other overblown claims to unremarkable behaviors. Similar to how ABA posits that all (autistic) behavior falls into one of four functions, a hallmark of unethical interventions is to classify any unwanted or visibly autistic behavior into a dire-sounding category. Someone stimming by lightly tapping on their head is not “self-injury.” Someone refusing to make eye contact with their teacher is not “inhibiting learning.” All these labels do is dilute and obscure what actual “self-injury” or “inhibiting learning” is and make it harder to help someone cope with or redirect these behaviors. Using the term “challenging behavior” begs the question: challenging to *whom*?

Even if an autistic person does require intervention, therapy, or support for a particular skill or behavior, it does not mean they must always be in autism-specific programs. It is helpful here to look at commonalities between autistic traits and symptoms or traits of other disabilities. Autistic people experience many of the same traits that people with other intellectual, developmental, learning, or psychiatric disabilities do and therefore could potentially benefit from the same therapies and services. Occupational and physical therapy, for example, are two therapies that benefit many people experiencing dyspraxia or apraxia – these could benefit autistic people with the same traits. Similarly, Shkedy et al. (2019) highlight that Dialectical Behavior Therapy (DBT), a widely used method of treating self-injurious behavior in non-autistic people, could also be useful to autistic people who engage in such behavior.

Non-specific services do not even need to be disability-specific or “therapeutic” in nature. Many autistic adults who want to learn to drive could benefit from the same types of driving lessons non-autistic people take. An autistic student who cannot handwrite assignments due to apraxia might receive an accommodation to type their homework instead. These solutions will not work for every autistic person, of course, but that does not mean they have no value.

Moreover, just because an autistic person enjoys a specific hobby or activity does not mean that activity is (or should be) “therapeutic.” An autistic person, for example, can enjoy swimming without that swimming being “aquatherapy.” Just like pathologizing unremarkable behavior is unethical and unhelpful, so, too, is therapizing any particular hobby or activity an autistic person enjoys. Autistic people, like all people, deserve to have hobbies, activities, relationships, and other social events that we enjoy without our enjoyment being labelled therapeutic or somehow part of our becoming more “typical.” We have the right to fun, joy, and connection for their own sake, not because they make us appear more “normal.”

To be clear, we are not stating that autism-specific therapies and services are *never* useful or helpful to autistic people. Many autistic people need individualized therapies and services that take into account their neurology and ways of interacting with the world, but these services must be ethical and person-centered. An autistic person’s need for higher

levels of individual support or customized services does not make it acceptable to subject them to unethical techniques. We are simply stating that many autistic people can benefit from the same services and classes that other people, disabled or not, do. All therapies and services must take into account the individual needs of the autistic person, but this does not equal funnelling autistic people into “autism-specific interventions” merely because we are autistic.

More Risk than Reward

There is no such thing as a zero-risk therapy or service. All therapies and services, regardless of their methodology and ethics, come with risks. For example, ABA often involves putting young children in 20-40 hours of therapy per week, on top of school and other activities. As Sparrow points out, “being Autistic doesn’t give a three-year-old child superpowers of endurance.” (Sparrow, 2016) The demands placed on young autistic children in ABA and similar therapies are more than we would expect of many non-autistic adults. A time commitment of 20-40 hours a week of *anything* for a young child, much less an intervention that they have no control over and cannot leave, is enough to cause stress and increase “challenging behavior.” This can trap autistic children in a vicious cycle, where harmful interventions equivalent to an adult full-time job exhaust and stress them out, leading to increased meltdowns and “challenging behavior,” leading to even more interventions. This becomes even more concerning given that a multisite randomized control trial showed that increasing time spent in an intervention had no overall effect on participant outcomes (Rogers et al., 2020); in other words, more treatment is not necessarily better treatment.

Interventions that require the same time commitment as a job also rob autistic people of time to relax, engage in hobbies, and socialize with peers, autistic or not. If the goal is to promote practical social skills and increase the autistic person’s overall happiness and satisfaction with their life, it would seem more practical to allow them access to hobbies, unstructured socialization, and things that increase their happiness rather than further therapy (Fiore, 2017). Autistic people are still *people* – we can still learn, grow, and develop, just like all people do.

Regarding the use of psychiatric medications among autistic people, the situation is similarly risky. Clearly, psychiatric medication (along with other types of medication, supplements, and medical diets) can and does have positive effects for many autistic people. But these medications come with major risks, including sedation, irritability, weight gain, and tardive dyskinesia⁴ (Accordino et al., 2016; Goel et al., 2018; Matson & Hess, 2011). While many of the drugs used to target autistic traits have been on the market for decades, and have been well-studied in other populations, there is not similar rigorous long-term data on their effects on autistic people, particularly autistic children (Yu et al., 2020). Furthermore, psychiatric medications are used as chemical restraint, or “the forced (non-consenting) administration of medications to manage uncontrolled aggression, anxiety, or violence in people who are likely to cause harm to themselves or others” (Muir-Cochrane et al., 2020, p. 1), on autistic people (Gulland, 2016; Lunsy et al., 2018; Matson et al., 2011; Webber et al., 2011). Chemical restraints, like other types of restraints, are disproportionately used on autistic people of color, and particularly Black autistic men and boys (Bhattacharyya et al., 2021; Fashaw et al., 2020; Foster et al., 2021; Pertsovskaya et al., 2021).

Given all of this, and given previously detailed concerns about adverse effects, reports of trauma during interventions, and links between autistic masking and suicide, we cannot stress strongly enough that for many interventions, the risks outweigh the rewards. If the goal of an intervention is to help the autistic person live a happier life on their own terms, these risks must be minimized. If the intervention has goals that do not center on improving an autistic person’s quality of life on their own terms, we stress extreme caution and skepticism with said intervention.

⁴ A disorder causing “involuntary, repetitive body movements” that occurs in 20%-50% of patients taking antipsychotic drugs, although it can and does occur for other reasons (Cornett et al., 2017).

ABA-Specific Concerns

The Brutal Beginnings and the Horrific Present

When examining the ethics of ABA, it is impossible to overlook its torturous history. This is perhaps best summed up by the title of a 1965 *Life* Magazine article about the work of O. Ivar Lovaas, the originator of ABA: “Screams, Slaps and Love: A Surprising, Shocking Treatment Helps Far-Gone Mental Cripples.” Lovaas’s work involved, among other disturbing methods, screaming at children until said children cried, withholding food and comfort until the children complied with his demands, spanking and slapping children for disobeying him, and, notoriously, subjecting children to electric shocks for behaviors as innocuous as staring at their hands (Chance, 1974; “Screams, Slaps and Love: A Surprising, Shocking Treatment Helps Far-Gone Mental Cripples,” 1965; Silberman, 2015).

It is important to note that Lovaas’s techniques were controversial even at the time, both among parents of autistic children and among his professional contemporaries. Anita Zatlou, the then-president of the Manhattan chapter of the National Society for Autistic Children,⁵ asked “What message is really received by the already disoriented autistic child/recipient of aversives? Can aversives create anxiety and, if so, might not the ‘treatment’ increase the pathological behavior?” (quoted in Silberman, 2015, p. 296). Even B. F. Skinner, whose work on operant conditioning in animals laid the foundation for Lovaas’s work, maintained that “To remain satisfied with punishment without exploring nonpunitive alternatives is the real mistake” (quoted in Silberman, 2015, p. 296).

This brutal beginning to ABA would be reason enough to hold its methods suspect, even if the current practice appeared different at first glance. But the field has never repudiated its roots, and aversive practices remain in use by some practitioners today. The Association for Behavior Analysis International (ABAI), which bills itself as “primary membership organization for those interested in the philosophy, science, application, and teaching of behavior analysis” (Association for Behavior Analysis International, 2021), hosted a symposium at their 2021 annual conference entitled “Challenging the FDA Ban on Electrical Stimulation Devices,” presented by employees of the Judge Rotenberg Center (Lowther et al., 2021). “Electrical stimulation devices” refer to the graduated electronic decelerator (GED), a painful electrical shock device “intentionally designed to be more powerful and painful than a police taser” (Brown, 2014, sec. Brief Background). The GED has been condemned by the United Nations Special Rapporteur on Torture as violating the rights of students at the JRC under the UN Convention against Torture (Méndez, 2013). As Neumeier and Brown point out, over 80% of the JRC student population is Black or Latinx (2020). In the half-century that disabled people and our allies have been fighting to close down the JRC (Brown, 2014, sec. Brief Background), ABAI has never condemned this practice, and continues to feature this organization at their conference.

While the JRC represents a particularly ugly example, it does not in fact violate the BACB’s “Professional and Ethical Compliance Code for Behavior Analysts” (Behavior Analyst Certification Board, 2014), as it currently stands. Although the code does contain a brief subsection on “Considerations Regarding Punishment Procedures” (§4.08), this subsection does not ban the use of any of Lovaas’s aversive techniques: screams, slaps, or electric shocks. Nor does the subsection on “Avoiding Harmful Reinforcers” (§4.10) address the use of food, attention, or other basic needs as a reinforcer. It merely states that behavior analysts should “minimize the use of items as potential reinforcers that may be harmful to the health and development of the client.” In other words, it’s okay to withhold food from a child to make them comply – but that food had better be healthy food. Together, the two subsections are still shorter than subsection 8.04, “Media Presentations and Media-Based Services,” which governs how behavior analysts can use media in their work and what they must do if they are to give a public statement. While the BACB is updating their code of ethics beginning January 1, 2022 (Behavior Analyst Certification Board, 2020), the updated code still does not contain any prohibition on any of Lovaas’s techniques. Even if it *did* contain a ban on these techniques, one would have to question why it took the BACB nearly a half-century to speak out against the abuse and torture at its roots.

Given all of this, it is impossible to say that the professional and certification organizations that govern the practice of ABA have any will or drive to condemn Lovaas’s acts, to prevent the use of harmful aversives and other unethical practices in today’s ABA, or to truly transform their field. The state of ABA, right now, is that of a hotel that was built with rotten wood on a shaky foundation without regard for the safety of its past, current, or future guests.

⁵ The National Society for Autistic Children is now the Autism Society of America.

ABA's Historic Ties to Conversion Therapy

ABA has been often compared to “conversion therapy” that aims to make LGBTQ+ people heterosexual and/or cisgender. The comparison is not without historical precedent: Lovaas also worked on a project which aimed to “cure” young boys of effeminate behaviors that put them “at-risk” of homosexuality (Silberman, 2015). Autistic writer and advocate Amy Sequenzia refers to ABA as “autistic conversion therapy,” saying, “Gay Conversion Therapy has a bad reputation now, even if it still happens. Both ‘treatments’ (tortures) have the same root. I want the supporters of ABA to own their objective. ABA: Autistic Conversion Therapy that uses torturous methods” (2016). Similarly, Crawley, in discussing modern attempts to ban conversion therapy, states “A lot of autistic people are gay or transgender and so you’re not banning conversion therapy for those transgender and gay people, they’re still getting it because they’re autistic” (Bettin et al., 2021). Milton, referencing a criticism of early conversion therapy, writes “These remarks are eerily familiar with regard to the reasons given as to why ABA is often administered upon neurodivergent people” (2018a).

Some behaviorists and ABA practitioners themselves have criticized Lovaas’s involvement in the developing conversion therapy. Lovaas and his graduate student George Rekers originally published their work in 1974; some of their contemporaries criticized the work as unethical at the time (Nordyke et al., 1977; Winkler, 1977). Since then, other behaviorists have also criticized Lovaas’s involvement (Conine et al., 2021; Inappropriate Opossum, 2021; Morris et al., 2021). In 2020, the Society for the Experimental Analysis of Behavior (SEAB) published a formal expression of concern on the study (Society for the Experimental Analysis of Behavior & LeBlanc, 2020) but did not retract the study altogether (Johnson, 2020). However, the majority of behaviorists and ABA practitioners, including the majority of those cited here, seem unable to acknowledge the clear ethical parallels between conversion therapy and ABA themselves.

Gibson and Douglas, in their article “Disturbing Behaviours: Ole Ivar Lovaas and the Queer History of Autism Science,” discuss how both ABA and conversion therapy are based in the idea that autism and/or LGBTQ+ identity are things that society shuns or shames, ergo, these are both things to be manipulated out of a person (2018). Pyne, similarly, points out that Lovaas used the spectre of institutionalization for autistic children, and incarceration for “effeminate” boys, to scare parents into pursuing therapy (2020). Lovaas stated that it was easier to manipulate a child’s behavior and abuse that child into appearing heterosexual, and cisgender, than put energy into advocating for social change, saying “[while] society probably could afford to become more tolerant with individuals with sex-role deviations, the facts remain that it is not tolerant and, realistically speaking, it is potentially more difficult to modify society’s behaviors than [the child’s]” (Rekers & Lovaas, 1973, p. 2). “It is potentially more difficult to to modify society’s behavior,” whether or not it is stated so explicitly, is a common justification for ABA therapy today. Given that conversion therapy is, obviously, unethical and has been condemned by many different health care professional organizations in the United States, along with the United Nations Human Rights Council (Madrigal-Borloz, 2020; *Policy and Position Statements on Conversion Therapy*, n.d.), this raises significant concerns about the morality and ethics of ABA and similar practices altogether.

All of this is to highlight the direct link between ABA and conversion therapy. It is not enough, as some have argued, to merely point out that the two practices share similarities. Conversion therapy, which is now widely shunned and outlawed in many jurisdictions, is a direct descendent of ABA, right down to Lovaas having participated in the development of both. The very techniques and basic underlying principles – namely, that “aberrant” behaviors can be eliminated through the right application of rewards and punishments – are the same between both practices.

Dehumanization of Autistic People

We have discussed a number of evidence issues surrounding autism interventions. We consider all of these ethical issues, because we believe it is unethical to subject someone to an intervention with a shoddy evidence base. However, there are further ethical issues; the first of which is the utter contempt and dehumanization with which ABA treats autistic people.

ABA classifies all behavior of an autistic person into four functions: to gain attention, to gain access to a desired item, to escape a demand or task, and to gain or escape sensory input (Alstot & Alstot, 2015; *Four Functions Of Behavior*, 2021). Many ABA interventions use this system to categorize *every* behavior an autistic person exhibits. This view of behavior inherently dehumanizes autistic people and minimizes our internal emotional and mental states. In ASAN’s earlier report, “First-Hand Perspectives on Behavioral Interventions for Autistic People and People with Other Developmental

Disabilities,” a participant criticized “therapists and teachers who saw just ‘behaviors’ to extinguish without considering the feelings and thoughts that might be motivating them” (2017).

This view of behavior portrays an autistic person less as a human and more as a machine that processes inputs into outputs. It ignores complex internal reasons someone may “act out.” It denies autistic people the human dignity and compassion that other people experiencing pain or discomfort receive. Reducing behavior down to four functions allows intervention practitioners, educators, and even parents and caregivers to stop any inquiry as to why an autistic person is actually behaving a certain way. It reduces the complex inner lives that autistic people – like all people – have and views us as too simplistic to have “real” emotions or motivations. Tellingly, this view of behavior is rarely, if ever, used as a treatment framework for non-autistic people.

Human behavior, including “challenging behavior” is not inherently manipulative or even necessarily directed at changing the actions of others. People who engage in self-injury or suicidal behavior, for example, may engage in it to reduce the internal emotional pain they feel, even though self-injury or suicidal behavior is clearly “challenging” to the person and those around them (Nock & Prinstein, 2004). Humans – all humans, regardless of neurotype – have complex, highly personal reasons for carrying out behaviors. No person, autistic or otherwise, acts *solely* as a reaction to the environment around them. To act as if this is any different for autistic people is a ghastly dehumanizing premise.

Autistic writer and educator Maxfield Sparrow points out what he terms the “fundamental flaw” of ABA and other similar therapies: the “Black Box,” or that “it’s designed to be able to glean [internal motivations] from observing behavior, not from social-emotional bonding between client and professional” (2018). Interventions that seek to change autistic behavior without understanding where that behavior is coming from and *why* are, effectively, trying to wallpaper over unwanted behaviors without addressing the root causes of that behavior.

Take, for example, an autistic child who is engaging in serious self-injury, to the point of needing emergency medical care to treat the physical outcomes. There are myriad reasons why this child might be self-injuring: sensory over- or understimulation, stress, physical discomfort,⁶ depression, anxiety, poor body image, and many others. ABA does not explore what these reasons are. It does not demand a full medical exam to ensure that the behavior is not caused by some bodily or mental need. It does not give the child different, less harmful ways of dealing with their emotions or ways to tell others that something is wrong. It does not even seek to explain to the child why their behavior is harmful or distressing (if it is not already immediately clear to them). It focuses, solely, on eradicating the “problem” behavior without providing any actual constructive support or solutions. It leaves the child worse off than they were even when they were self-injuring: now, not only are they still dealing with whatever distress was causing their self-injury in the first place, but they are unable to engage in behavior that expressed or alleviated, at least temporarily, their distress. Even in the worst case scenario – a child engaging in uncontrollable self-injurious behavior that leads to major physical harm – ABA is still not a solution.

A behaviorist framework is one reason therapies may target only external behaviors without delving deeper into autistic psychology, neurology, and mental well-being. Another is that there has been little research into developing measurements of autistic well-being and mental health, especially among autistic people with intellectual disabilities and non-speaking or unreliably speaking autistic people. There are few, if any, psychological assessments created specifically to measure mental health in autistic people, particularly non-speaking autistic people. Measuring language/communication skills, IQ, adaptive skills, or “autistic traits” is not the same thing as truly measuring mental health, self-determination, self-esteem, sensory regulation, or how prepared a person feels to deal with their environment.

⁶ Endow gives the example of a child who engaged in self-injury because they had a severe, untreated case of head lice (2019).

“New ABA” is Still ABA

At ASAN, we have heard from parents who say that ABA as practiced in their family is different from “traditional” ABA – describing interventions that are “holistic,” “play-based,” or “naturalistic,” that focus on communication or life skills rather than on “normalizing” a child’s behaviors, and that take a respectful approach to an autistic child’s existence and needs. This is sometimes termed “new ABA.” It can be hard to determine what is really going on in any given situation. If these practices are indeed ABA, we stress that they are still harmful. We also stress that many practices termed “new ABA” are not, in fact, ABA at all.

Sometimes, parents are describing something that still sounds like ABA, in that the intervention still uses reinforcements to modify . An intervention that, at its core, still uses ABA techniques, is still ABA and still unethical, no matter what other methods it may use. It still carries the same risks of harm, the same lack of acknowledgement of those risks, and the same lack of rigorous supporting evidence. Fundamental modifications of who an autistic person is – or attempts to do so – do not suddenly become acceptable just because the techniques used are less obviously cruel.

A core component of “new ABA” is contrasting its practices with the “old,” torturous practices of Lovaas and his ilk. Leaving aside that Lovaas’s practices are hardly consigned to the past (see the section “The Brutal Beginnings and the Horrific Present”), an intervention being less abusive than a different intervention does not mean that intervention is inherently ethical. Our ethical concerns with ABA go far beyond whether an intervention uses electrical shocks or withholds food to enforce compliance. To again use the metaphor of the rotting hotel, we would still advise others to avoid renting a room there, even if the owners assured us they had repainted and brought the electrical wiring up to code.

ABA that is play-based is still ABA. It is still harmful to try and modify autistic traits or the appearance of autistic behavior, even if it is couched in toys and the appearance of fun. Play-based ABA takes the activities an autistic person enjoys and turns them into ways to attempt to make the person less autistic. For example, if an autistic child collects shoelaces, the ABA therapist might hold a shoelace near the therapist’s eye in order to elicit eye contact. Or, the therapist might do a puzzle with a child, but require the child to look at the therapist and verbally request each piece of the puzzle. While this may seem “nicer” than a traditional discrete trial, the end goal is still to modify the child’s autistic trait. Using play to train a child to appear less autistic also warps the experience of play for the child. We want to stress that we do not believe that *all* play-based therapy is bad or harmful. We realize that play-based therapies can be incredibly useful, especially for nonspeaking autistic children. But play-based ABA, specifically, is harmful because it is still a form of ABA.

When ABA approaches are used to teach language or speech, we are concerned because the behaviorist approach to language development has been discredited (Chomsky, 1980). ABA approaches to language development, including Verbal Behavior, ignore decades of well-established research on how children, including autistic children and children with significant structural language impairments, learn language (Birner, 2021; Feldman, 2019; Kuhl, 2000). When children appear to gain language in these programs, it is important to understand that this progress is *in spite of*, not because of, ABA’s outdated and disproven methodology. Autistic children are best supported by a Speech-Language Therapist familiar with best practices for supporting their specific language challenges, including augmentative and alternative communication systems, or AAC. Teaching language via ABA is ineffective and not worth the harm it causes to those subjected to it.

Similarly, there are better ways to teach other core life skills, such as through non-ABA occupational and physical therapies. We once again reference that there are non-autism specific supports that can and do help autistic people build skills and lead more independent and self-directed lives. An autistic person with severe apraxia, for example, could benefit from some of the same occupational and physical therapies, along with the same assistive technology, as apraxic people with other developmental disabilities. It is also important to remember that just because an autistic person needs a highly individualized or adapted intervention to help them, this does not mean they need ABA. ABA does not have sole claim to individualized or customized therapies and services.

We sometimes hear from parents that their child likes their ABA therapist or assents to an ABA intervention. We would still have concerns in these situations – liking one’s therapist does not make the intervention effective or ethical. Our

ethical concerns with ABA (and all other autism therapies and services) do not center around the likeability of the practitioner or whether they can build a rapport with the autistic person.

More and more, we hear families emphasizing the benefits of ABA while describing services that are not ABA at all, especially for older children and children with typical-sounding speech. These families may be working with a practitioner licensed as a BCBA or with other ABA-related credential--but that does not mean the provider is using ABA in their practice. Just because someone is licensed to practice ABA does not mean every service they provide *must* be ABA. This includes BCBA's providing multi-disciplinary services like addressing interoception and self-regulation, providing cognitive strategies for coping with stress, addressing executive functioning or advanced conversational skills, providing employment supports or support navigating the community, and other similar services. Crucially, these techniques and services *are not recognized as ABA* by ABA professional organizations or journals.

We also acknowledge an additional complexity: the matter of insurance coverage for therapies and services influences how providers label therapies and services in order to be covered by insurance. While insurance coverage for a broad base of services and therapies is becoming more commonplace, some insurance plans will only cover ABA interventions for autism. Ergo, non-ABA intervention specialists will sometimes market or bill their work as ABA, even when it is not (Sparrow, 2016). This leads to a conundrum: some practices that call themselves ABA for insurance or payment purposes may be perfectly ethical non-ABA practices. This creates a genuine quandary for autistic people and our families seeking services. Laying aside the ethical questions of mislabeling one's therapy for insurance purposes, we are also concerned with how providers may use the excuse of "only calling an intervention ABA for insurance purposes" to avoid examining the goals and ethics of a given service.

Finally, we acknowledge that some behavior is genuinely dangerous (e.g., self-injury that results in substantial physical harm to a person) and must be changed or redirected as a matter of safety. But we believe that people who do dangerous things still deserve better support than ABA. A person struggling with self-injury or aggression has real needs that deserve a closer analysis than "attention seeking, escape/avoidance, access to tangible objects, or sensory stimulation." Research shows that most people in such circumstances have underlying medical, mental health, and lifestyle challenges – and many have not been supported to access robust communication options (Kripke, 2016a, 2016b, 2016c, 2018; Smull & Harrison, 1992). We believe that people deserve to have their underlying needs met, and that autistic people do not generally try to harm ourselves or others when we feel we have better options.

We also stress that so-called "dangerous behavior" is sometimes in response to poor treatment when people around the autistic person *expect* dangerous behavior. In their report "Supporting People With Severe Reputations in the Community," Smull and Harrison (1992) write:

There are a number of individuals whom we have taught that merely complaining about a program produces no change. "Non-compliant" behavior (otherwise known as non-verbal complaining) results in behavioral control programs. We teach these individuals that we will only listen to extraordinary displays of aggression or property destruction. We then say that they "failed" in that program and move them to another program. Ironically the "failure" often reflects the success of the individual in learning what it takes to get our attention and cause us to change the placement.

Smull and Harrison "Supporting People With Severe Reputations in the Community" 1991

If a person is given no choice but to engage in "dangerous behavior" or "act out" in order to have their needs met and make change in their lives, that is what they will do. Autistic people do not exist in a vacuum; we are affected by our environments and the expectations of those around us. This expectation of poor behavior disproportionately affects autistic people of color, and especially Black autistic people. In a school setting, this can look like Black autistic students being disproportionately labelled as having emotional or behavioral disorders and then being shunted into classrooms where little is expected of them other than to "act out" (Harry & Klingner, 2006, p. 147)

No One Specific Intervention

For all the reasons we have covered in this paper, ASAN believes that ABA cannot be practiced ethically, regardless of the circumstances or context, and that ABA is always unethical and inappropriate. ABA is fundamentally dehumanizing, ineffective, and dangerous. While there have been various attempts to reform ABA and make it more palatable (sometimes termed “new ABA”), our position is that no amount of reform or changes can make ABA an acceptable practice.

However, the potential ethical pitfalls in autism interventions are not specific to any one service or therapy. Any autism intervention can have ethical failings or treat its participants poorly. What an intervention calls itself is less important than its specific features and whether it follows the ethical principles outlined in this paper. A singular focus on avoiding ABA may not flag other therapies or services that market themselves as alternatives to ABA while still embracing unethical techniques, holding goals and aims of indistinguishability, casting autistic traits as inherently negative, and engaging in other unethical behaviors. Avoiding ABA methodology is necessary, but not sufficient, for ethical autism service provision.

Self-advocates’ serious concerns about the ethical implications of a wide range of non-ABA autism therapies and services require an in-depth and constantly re-evaluated examination of the goals and methodologies deployed in any therapy, not only by the intervention in general but also in the specific context a given client experiences. There is no one “magic phrase” that makes a therapy automatically ethical. The only way to know whether an intervention is ethical is by examining it closely from every angle and researching it thoroughly. Autism therapies and services should be held to the same rigorous standards that other medical, psychological, pharmaceutical, educational, and occupational therapies and services should be. The only way to know if an intervention is ethical, effective, and appropriate for a specific person is to research said intervention in-depth and find a broad range of perspectives on it. Ethical evaluations of an intervention cannot be complete without including perspectives of people who have undergone that intervention.

Moreover, even if an intervention is ethical in general, that does not mean it is ethical in any given application or appropriate for any one autistic person. This paper has largely focused on the ethics of therapies and services at a general level, but the specific individual experience a given autistic person has of their specific services and practitioners is paramount. If an intervention targets skills that a person does not need or has no interest in learning, it is probably not a useful or appropriate intervention for that person. A clinician can misapply or misuse an intervention even when there is a clear ethical framework in place. Whether an intervention is ethical *overall* cannot be the only factor on which one evaluates it; one must also consider whether it is a useful and supportive experience for the autistic person in question.

In looking at any intervention, there are a few starting questions to ask about its ethics:

1. What are the goals of the intervention, both stated and unstated? Who is involved in coming up with and writing those goals?
2. What beliefs about autism are implied by the intervention? Why does it target a specific skill or behavior?
3. Who benefits most from the intervention? How do various people involved in the intervention (the autistic person, their parents/family, their support people, etc.) benefit?
4. Would you consider this intervention ethical if it was performed on a non-autistic person?
5. What are the possible (or known) long-term effects of the intervention on the person? What are the possible (or known) long-term effects of not having the intervention on the person?

The answers to these questions will reveal more about the intervention in question than any one name or label will.

Ethical Standards and Guidance

After thoroughly exploring the literature and summarizing some of the ethical questions inherent in different autism therapies and services, we derived the following set of ethical principles for autism services. We have divided these into four categories: first principles and core ethical statements, “always acceptables” and practices to promote in autism supports, “never acceptables” and red flag practices that are abusive, and ethical guidelines for research into autism therapies and services. We emphasize that these guidelines and principles apply to *all* therapies and services autistic people go through, regardless of whether those therapies and services are autism-specific or what the therapies and services call themselves. These principles are not intended to be exhaustive, but to provide a starting point for service providers, researchers, and educators to examine their practices and identify initial areas for change.

First Principles and Core Ethical Statements

Autistic people are people. We are human beings with thoughts, feelings, wants, needs, and dreams. We experience pain and joy, just like non-autistic people do. Our internal experiences and inner lives are important, even if they are different from those of non-autistic people. We have the same human rights as non-autistic people. We may struggle with things that non-autistic people do not but this *does not make us less human*. **Autism is not a justification to abuse us or subject us to harmful therapies against our will.**

This statement is true of all autistic people. It is true of autistic children. It is true of autistic adults. It is true of autistic people of color. It is true of autistic women and non-binary people. It is true of non-speaking autistic people. It is true of autistic people with intellectual disabilities. It is true of physically disabled autistic people. It is true of autistic people with mental health disabilities. It is true of autistic survivors of seclusion, restraint, institutionalization, and forced/coerced/involuntary treatment. It is true of any and all multiply marginalized autistic people. It is true of all autistic people. **There is no group of autistic people that is okay to abuse or harm because they are autistic or because of other parts of their identity.**

Autistic traits in and of themselves are not acceptable targets for intervention. Therapies and services must have a more concrete and substantial rationale for targeting a particular trait than “it is an autistic trait” or “it makes this person look different.” Autistic people have full, rich selves. We do not exist to be made “less autistic” or “more typical.”

Autism and autistic people do not exist in a vacuum. We are affected by our environments and the actions of others around us. It is not solely the autistic person’s duty to “fix” communication breakdowns and differences in experiences between us and non-autistic people. It is also the duty of non-autistic people around us to help fix these breakdowns – and also realize when something is less a problem to be solved and more a matter of different communication styles.

Autistic people have the same right to give, and refuse, informed consent and assent as our non-autistic peers. We have the same right to information about the services we receive. If we cannot give informed consent to a given service (for example, an autistic child who cannot legally consent), we still must be given the chance to give or refuse assent.

Therapies and services must focus on improving the autistic person’s quality of life by increasing opportunities for and access to self-determination, communication, self-advocacy, and other goals that are important to the autistic person in question. The autistic person must be involved in setting those goals. If an autistic person cannot make their goals clear (e.g., because of age or communication barriers), their goals should be set based on their team’s most reasonable guess of what will best allow them to lead a self-determined life and what needs and wants they are currently demonstrating. If a goal must be set against a person’s wishes (e.g., teaching someone not to run into traffic so they can safely cross the street), it must be explained to them why it is so important and implemented in such a way that the person maintains as much control over the intervention as possible.

Autistic children thrive when they have the supports they need to succeed, just like any other child. Autistic children often respond well to structured, accessible interaction with an adult who is focused on them, supporting their communication and engagement, sharing learning and enjoyment, and providing a warm, positive relationship – as would any child. **Providing these kinds of supports is crucial, and should not be conflated with “treating” autism.** An autistic child who does well or appears more visibly engaged with these kinds of supports in place isn’t becoming less autistic – they’re simply showing what they are capable of with the right support.

Therapies and services should use knowledge that we have about humans in general to best support autistic people.

Therapies and services should treat autistic people as capable of learning, growing, and developing, just like all people do when well-supported. Therapies and services must not portray autistic people as a nebulous “other” type of human who cannot learn at all from the same techniques as non-autistic people.

Supports don’t need to be autism-specific to help autistic people. For example, an autistic child who has trouble with handwriting might benefit from the same type of occupational therapy and assistive technology (such as typing assignments rather than handwriting them) that a non-autistic child would. Supports also don’t need to be specifically for disabled people to help. For example, while some autistic adults who want to drive will require specialized instruction, many autistic adults just need the same kinds of driving lessons that non-disabled people have.

Autistic people have a wide variety of interests, hobbies, and activities we enjoy, just like non-autistic people. **We have the right to engage in these activities without it being a “therapy” or “intervention.”** Our hobbies do not exist to be tools to make us more “normal.” Even if we need support or accommodations to engage in an activity (e.g., an autistic person who needs a support person to accompany them to a weekly board games night), that should not make the activity a therapy.

What the intervention calls itself is not as important as what it actually is. There are therapies and services that are largely ethical but call themselves ABA because that is the only way insurance will cover them. There are interventions that insist they are not ABA or they are “safe” alternatives to ABA, despite being rooted in ABA or having significant unethical elements.

“Always Acceptables” and Practices to Promote

Trauma-informed approaches and making sure practitioners are trained in trauma-informed care.

Cultural competency and cultural humility among practitioners⁷ and making sure practitioners provide care and services that are sensitive and relevant to the autistic person’s culture, community, and social background.

Ensuring that the autistic person always has **an effective and robust method of communication as the first priority.** An “effective and robust” method of communication means a method that allows the person to communicate whatever they have to say, does not limit them to simple requests, allows them to create grammatically correct sentences if they choose to, and is relatively easily understood by those around them. If speech is not a reliably effective and robust method of communication for the autistic person, they should be provided with an augmentative and alternative communication (AAC) system. Effective communication also means working in the language the person is most fluent in and most comfortable using, even if this is not the dominant language of the area. Ensuring effective and robust communication for AAC users also means supporting them in learning how to use, program, and care for their systems and devices. For some autistic people, this process may take a lifetime. Support should be provided for as long as the person needs or desires it.

Giving the person space and time to move around (including stimming), take breaks, and feel comfortable. Explicitly **encouraging the autistic person to communicate** (in whatever ways they need to) if something is wrong or if they don’t like something, or, conversely, what they *do* like or want during the intervention

Explicitly encouraging the autistic person to **communicate their goals for the intervention. Including the autistic person as a core member** of all goal-setting/planning the course of the intervention and any associated meetings, such as IEP meetings or support planning meetings.

Presuming competence: presuming that, with the right supports, the autistic person is capable of learning, thinking, communicating, and gaining new skills. A practitioner who presumes competence focuses on identifying the supports an autistic person needs in order to meet their goals, rather than making assumptions about what they can and cannot do.

⁷ Cultural humility is “a lifelong process of self-reflection and self-critique whereby the individual not only learns about another’s culture, but one starts with an examination of her/his own beliefs and cultural identities” (Yeager & Bauer-Wu, 2013, p. 2). It is contrasted from cultural competency, or the “attitudes, knowledge, and skills necessary for providing quality care to diverse populations” (Calvillo et al., 2009, p. 138).

Minimizing physical contact to what is absolutely necessary for the intervention to work. **Asking for consent every time** physical contact is necessary and informing the person of exactly what the physical contact will be. For example, in some kinds of physical therapy, contact between the therapist and the client will be inevitable. But asking for consent (“is it okay for me to touch your shoulder now?”) and telling the person what the contact will be (“I’m going to put my hands on your upper arm and slowly rotate your shoulder.”) is important!

Distinguishing when an issue is less something for the autistic person to do differently and more something to change in their environment or address in the behavior of others around them. For example, if an autistic person has meltdowns at school everyday because they find the lighting too harsh, changing the lighting in their classroom instead of trying to get them to tolerate it. If they have a meltdown every time their neighbors mow the lawn, working with the neighbors to find a time when the person won’t be around and mow the lawn then.

Figuring out when the issue is something that could be resolved with assistive technology and equipment. (This does not need to be disability specific equipment.) For example, if someone is sun-sensitive to the point it causes meltdowns, make sure they always have a hat and dark glasses with them. If someone chews holes in their shirts when they stim, buy them stim toys specifically designed for chewing.

Targeting services and supports towards specific skills and problems (for example, learning how to drive, finding a job, reducing frequency of self-harm) rather than “autism” or broad diagnoses in general. Similarly, when providing support to gain specific skills or address specific problems, examine if the supports truly need to be autism-specific, or if there are generic supports used by a range of people with disabilities that might meet this person’s needs.

Working with other healthcare providers to **ensure an issue is truly behavioral, not medical, in nature.** For example, someone who has severe migraines that manifest as meltdowns where they curl into a ball, holding their head, needs to be assessed by a neurologist, not put into an intervention to change how they behave during a meltdown. If there is a sudden change in someone’s behavior and they cannot explain why, the first course of action should be a medical evaluation to rule out or identify medical causes.⁸

Provide support in inclusive settings (those where disabled and non-disabled people are together) whenever possible. Therapies and services (especially school-based therapies and services) should be offered in the least restrictive environment possible. Whenever possible, **offer services in a setting of the autistic person’s choice** (for example, home, clinic, school or day program). If an intervention is being offered for autistic people in a mixed setting (e.g., autistic students in a mainstream classroom), it should be offered without removing or pulling out the autistic people as much as possible.

Rejecting functioning labels and other unclear, undefinable ways of labeling a person rather than identifying their specific needs. Avoiding pejorative labels like “low-functioning” for autistic people who have high support needs, intellectual disabilities, who are non-speaking or engage in self-injury. Similarly, avoiding labels like “high-functioning” for people with lower support needs, as these labels are often used to deny people services they would benefit from.

Acknowledging, celebrating, and encouraging what a person can do and is good at. Finding ways to connect a person’s strengths to their goals. This should also include finding ways to **integrate the autistic person’s interests into the intervention** – not as a way to modify their behavior, but to engage with that person and increase the chances they will find the intervention meaningful.

Embracing the idea that all people (autistic and non-autistic alike) grow up and change on different developmental tracks. An autistic child may develop some skills later than non-autistic children, or in an unusual order. While knowledge of developmental stages can be useful in assessing and diagnosing developmental disabilities, including autism, they are not a roadmap that must be forcibly followed. Therapies and services should be helping autistic children develop skills because they are relevant to their personal goals – not because they are next on the typical timetable.

⁸ Clarissa Kripke, the director of the Office of Developmental Primary Care at UCSF, has written extensively on the need for medical evaluation of behavior changes in autistic people and other people with intellectual and developmental disabilities (2016a, 2016b, 2016c, 2018).

“Never Acceptables” and Red Flag Practices to Avoid

Targeting “undesirable” traits or behaviors that are common in all people of a certain age, autistic or not. In other words, therapies and services should not pathologize normal/typical behavior for the age group of the client. An autistic 5-year-old being unable to sit still for long periods of time or an autistic 15-year-old wanting to play video games all day aren’t “autistic behaviors,” they’re just things that most 5- or 15-year-olds go through. Holding autistic people to higher standards than their non-autistic peers merely because they are autistic is unacceptable.

Deeming a trait or behavior “desirable” or “undesirable” based on whether it is typical of people of a certain age.

Therapies and services should not force autistic people to engage in a behavior simply because most people their age do it or discourage a behavior because most people their age do not do it. For example, discouraging a 15-year-old from talking about Dora the Explorer because “that’s not what teenagers talk about.” We realize that there are some activities that most people learn at a certain age (e.g., toilet training toddlers or teaching elementary school children to read). We do not object to autistic children learning these skills because their similar-age peers are learning them, so long as there is a more substantial reason for them learning the skills than “it’s just what people their age do.”

Stating or implying that there is only one possible or “correct” way for all people to learn a skill (e.g., learning to speak, learning to solve math problems). For example, insisting that visual joint attention is an inherent requirement for developing speech or that nonverbal communication is a prerequisite for symbolic thought in all humans. Even among non-autistic and non-disabled people, there is a tremendous diversity of how people learn any given skill. There are as many developmental paths as there are humans. Just because one way of learning or developmental path is more common does not make it the “correct” one or the only possible one.

Conflating impairments in areas like speech or motor skills with the absence of internal processes and feelings.

For example, many autistic people have speech disabilities. A difficulty in producing oral speech is distinct from an impairment in language processing, which the autistic person may or may not struggle with as well. But often, nonspeaking people are automatically assumed to have language disabilities. Similarly, autistic people are known to experience varying degrees of difficulty with motor planning and other motor skills, which can impact our speech, facial expressions, and how we appear to relate to other people or our environment. This means that it is dangerous to make assumptions about what an autistic person understands or how they think or feel based on these things.

Teaching autistic children to assume that their viewpoint or way of being in social situations is wrong, and that they must defer to their neurotypical peers, whose way of being is “correct.” This can be done by explicitly telling autistic children repeatedly that their way of social interaction is wrong. For example, it is obviously harmful to tell an autistic child that they are approaching social situations incorrectly because they have an inflexible mind, so they should default to copying their peers. But it is also harmful to more implicitly show an autistic child that, if there is a discrepancy between what they are doing and their neurotypical peers, their neurotypical peers will be held up as an exemplar.

Punishing autistic people differently than non-autistic people for the same behavior solely on the basis of autism/related diagnoses. For example, if a non-autistic speaking child swears, their teacher might tell them “we don’t use words like that in class, it’s not appropriate right now.” But if a non-speaking autistic child who uses an AAC device swears, the teacher might take their device away from them so they can’t talk at all.

Focusing on non-specific “social skills,” to the detriment of all other skills. Autistic people, like all people, need and deserve support on a wide range of skills and activities, not just those related to socialization or interpersonal interaction. Moreover, while most daily activities have *some* social component, knowing how to navigate a general social situation is not enough to navigate many activities. For example, an autistic person who cannot navigate a bus system on their own due to sensory or executive functioning barriers would probably be poorly served by social skills instruction to learn this particular skill. Or, an autistic person applying for jobs might benefit somewhat from generalized social skills support, but would also probably need help with application-specific skills. When the balance of time spent shifts too far in favor of social skills, other crucial skills suffer.

Social skills training that encourages autistic people to merely “act neurotypical” rather than presenting neutral information for navigating social interactions. Autistic people may need support in interpreting social situations or thinking through how to respond. There are ways to provide helpful information, but the goal should be to provide

that information in a neutral way so we can decide what we want to do with it. Too many social skills interventions simply promote masking or camouflaging autistic traits, or inflexibly presume there is one correct way to handle a given situation. Support in thinking through social scenarios should not be seen as *training*, but should aim to empower autistic people to self-advocate and give us tools to make the social decisions that we decide make the most sense for us. We realize that there are examples of social skill-type supports that focus on a specific scenario or subset of skills (e.g., a sexual education class or training on job interview skills). We do not object to these types of supports, especially if they are offered to the autistic person's non-autistic peers as well.

A goal of indistinguishability, or making the autistic person appear “normal” or exactly like their non-autistic peers.

A goal of reducing stimming. In some rare cases, a person might express they want to reduce a stim for a practical purpose; for example, someone who communicates using an AAC device and stims by hitting their device at random, to the point where they are distressed that they cannot use their device to communicate. As we addressed above, there are some stims that a person may want or need to redirect as a matter of safety. But even when there is a very good reason to stop or modify a particular stim, the **goal should never be to eliminate stimming entirely**. The goal should be to help them find a stim that does not have the same negative effects (for example, someone who is distressed by hitting their AAC device might get calming input by squeezing a stim toy instead).

Using restraints or seclusion of any kind.

Using aversives of any kind.

Abuse or neglect of any kind, including, but not limited to, physical, verbal, emotional, sexual abuse.

Using basic needs (for example, food, drink, toys, favored objects, breaks, change of activity, attention, special interests) **as rewards.**

Withholding basic needs (for example, food, drink, toys, favored objects, breaks, change of activity, attention, special interests) **as a punishment**

Hassling, harassing, coercing, or annoying an autistic person who has communicated “no” until they say “yes.” Coerced consent is not consent.

Knowingly or intentionally overriding someone’s “no.” We recognize that sometimes caring for children requires compelling a person to do something they do not want to do (e.g., a child who needs to get a vaccine but is scared of needles). We are not referring to such instances here, but rather when interventions portray the mere *act* of saying no as “non-compliance” and teach the autistic person that their right to say “no” does not exist.

Using “exposure therapy,” or teaching autistic people to “tolerate discomfort” in and of itself, as opposed to giving us tools to self-regulate, helping us reduce and control exposure to painful stimuli, or changing our environment to reduce exposure to triggers.

Patronizing/infantilizing language and actions, such as treating an autistic person as younger than they are. For example, speaking to an autistic teenager in a “baby voice.” We stress here that this does not mean autistic people should be kept from engaging with interests atypical for their age group (e.g., preventing a teenager from watching Sesame Street because “they’re too old for that”). We also stress that this does not mean autistic people should be denied accommodations such as information in Easy-Read or plain language or simplified instructions merely because these things use simpler language, if this is an accommodation a person needs.

Using “mental age,” e.g., saying “this person has the mental age of a 5-year-old” of someone who is not actually five years old. Using mental age is offensive and demeaning to autistic people, and especially autistic people with co-occurring intellectual disabilities (Smith, 2017). Autistic people, regardless of our support needs, are the same “mental age” that our bodies biologically are. An autistic adult with an intellectual disability is not a 5-year-old in an adult’s body; they are an adult with a lifetime of experiences, knowledge, and relationships, who also is autistic and has an intellectual disability.

Using deficit-based thinking, or focusing mainly on what an autistic person cannot do or has trouble with.

Touching autistic people unnecessarily (for example, using hand-over-hand tactics).

Portraying an intervention as “the only way [the autistic person] can learn.” While autistic people may share certain general cognitive styles and differences in ways we learn, think, and communicate, we have as many learning styles as non-autistic people do. There is no one ultimate autism intervention that will work for every autistic person. While some autistic people do need heavily individualized services and one-on-one support to learn, this does not mean that they cannot learn using a variety of methods if given the proper supports. We urge people to be wary of practitioners who claim that their interventions are the “only way autistic people will learn” or that they are the only people who can save us.

Portraying autistic people as some kind of nebulous “other” to whom general knowledge about humanity does not apply. The fields of child development, educational psychology, and many others offer plenty of useful information applicable to autistic people, who are first and foremost human beings. We can acknowledge common differences in how an autistic person might process or express something without treating autistic people as inhuman aliens who are incapable of human emotions or relationships, unable to share any common human experiences, and who cannot ever learn, develop or change.

Asserting that an autistic person will never “improve” without multiple hours of a specific therapy/intervention per day.

Subjecting an autistic person to multiple hours of intervention per day, to the point where the person is prevented from other important life activities (including rest and relaxation), the person is obviously in distress, or there is no observable purpose or benefit for the excess hours of intervention. This does not need to be multiple hours of *one* intervention per day; it can be the sum total of multiple interventions or interventions on top of other necessary events in the person’s day, such as school.

Predicating certain types of services or supports (and funding for those services and supports) on the autistic person/their family/supporters accepting a different type of intervention. For example, an autistic person on Medicaid who wants to have their waiver pay for environmental modifications to replace harsh fluorescent lighting in their apartment should not be required to undergo ABA to help them “tolerate” fluorescent lighting before Medicaid pays for the modification.

Predicating services and supports on an autistic person already possessing certain skills or demonstrating certain behaviors, unless those skills and behaviors are absolutely necessary for the intervention to proceed safely. For example, autistic children can learn academics without being “table ready.” Similarly, autistic people should be provided access to robust AAC from the start, instead of having to prove they can use more limited artificial systems first.

Requiring autistic people to give up or not use their assistive technology, unless there is a clear and unavoidable reason why the intervention could harm the assistive tech and a suitable alternative is offered. For example, telling someone they can’t use their AAC device in a class about developing relationships is wrong; telling someone they can’t use their AAC device in the pool during swim therapy might be understandable if getting the device wet would cause it to stop working. In that instance, the person should be offered an alternative that can get wet, like a laminated letterboard or a whiteboard to write on.

Principles for Research into Autism Therapies and Services

Therapies and services must be developed and researched with autistic people as part of the core research and development team. Autistic feedback needs to be considered and respected at all points of the research, formulation, development, and administration of the therapy or service. There should be multiple autistic people on the research and development team, representing a diversity of opinions, experiences, and support needs. Token inclusion of a single autistic person is not acceptable. Autistic people on the research team should be considered experts on the social acceptability of the research – whether autistic people would consider the research and its aims and potential outcomes acceptable – and non-autistic researchers should defer to them on such matters.

Intervention research should address the autistic person’s *experience* of the intervention, including their internal experiences and well-being alongside external/visible behaviors and reactions.

Therapies and research on therapies should prioritize outcomes that matter to autistic people, such as self-determination, communication, sensory processing and self-regulation, self-advocacy, independent living

skills, executive functioning, mental health, and overall well-being, **rather than the reduction of visibly autistic traits.**

The creators, practitioners, and professional associations of developmental therapies and other alternatives to ABA should prioritize rigorous, high-quality research of their services. We have shown that the evidence base for ABA is quite weak – but so is the evidence base for many other approaches. The lack of solid research prevents good services from being widely adopted, and limits the willingness of public and private insurers to pay for them. **Autistic people deserve access to evidence-based options, and we have the right to know which approaches are shown to help us reach our goals most effectively.**

Researchers should make sure that their research on autism includes all kinds of autistic people – including autistic people of color, non-speaking autistic people, autistic people with intellectual disabilities, autistic people with mental health disabilities, autistic people with co-occurring medical conditions, and autistic people with higher support needs. These groups should be represented as partners in participatory research, not just as research subjects.

Research into autism services should prioritize developing best practices for working with autistic people who are currently the most poorly served by existing services: non-speaking autistic people and autistic people with intellectual disabilities, especially people in those groups who have co-occurring mental health disabilities or who may struggle with self-injury or aggression. Too often, autistic people in these groups are not offered any services other than ABA. This is unacceptable. There must be a significant investment in research to develop best practices for delivering ethical, comprehensive services to autistic people with the highest support needs, including mental health services and communication supports.

Qualitative research and non-scholarly writing about autism services can be just as, if not more, important as quantitative research. Autistic people (especially autistic people of color, autistic women and non-binary people, autistic young people, autistic people from the Global South, nonspeaking autistic people, and autistic people with intellectual disabilities) have been systematically excluded from academia. Interventions must not discount criticism solely on the fact that it is qualitative and/or non-scholarly.

Intervention research must use the same human subjects research protocols that research on non-autistic participants use. Autistic services research has long exploited autistic people and subjected us to unethical and unsafe research practices with little to no oversight. We stress that autistic people, with the proper supports, are still eminently capable of taking part in research studies, but that our autism is not a reason to lower ethical standards or research participant protections for us.

Autistic people must be given the accommodations we need in order to give informed consent/assent and to take part in the study. These accommodation can include, but are not limited to, plain language and Easy-Read versions of materials, extra breaks during sessions, use of an augmented/alternative communication (AAC) device, having a support person with them if possible, and being able to familiarize themselves with the study team and materials before they participate in the study.

There must be protocols in place to ensure that autistic people are able to give continuous informed consent/assent during the study, not just once at the beginning of the study or at designated points within the study. Researchers should develop language for asking for continued consent/assent (e.g., “this is voluntary and there will be no bad consequences if you don’t wish to continue – do you want to stop?”) during the study. Researchers must honor any and all requests to stop from the autistic person immediately and without protest.

Research on autism services should be held to the same quality standards as research outside of the realm of autism. Autistic people deserve access to services and supports that are truly evidence-based, with rigorous research backing and high ethical standards.

Practitioners and researchers should be upfront about their conflicts of interest and how these affect their practice, research, and publication. Journals, conferences, and professional organizations that publish and promote research, education, and professional regulation of therapies and services should adopt a standardized code for disclosing conflicts of interest.

Practitioners of an intervention should take criticism of that intervention seriously, especially when that criticism comes from autistic people who have gone through the intervention.

Practitioners should encourage the autistic person, as well as their parents, guardians, caregivers, and/or support staff, to **report any possible adverse health events**.

Conclusion

Autistic people have expressed a wide array of ethical concerns with current autism therapies, as well as suggestions for reforming autism interventions both on an individual and social level. Some, but not all, of these concerns are reflected in scholarly writing and research on autism therapies. While the majority of scholarly critical work from non-autistic researchers on autism therapies and services tends to focus on ABA, work from autistic researchers and autistic people in general tends to take a more broad-base view of the concept of autism intervention in general, including other methods and categories of intervention. The ethical principles outlined above provide a starting point to create a framework for reforming autism interventions and creating more just and ethical services that focus on the needs, wants, and well-being of autistic people, rather than the preferences and assumptions of those around them. We support efforts by autism intervention professionals to integrate this framework into their specialities and programs when possible, and to change methodologies when not.

Individual autism intervention professionals can incorporate some of our recommendations into their own practices; however, some recommendations must happen at a more systematic level. There *must* be greater regulation, both through professional licensing organizations, and through government agencies, of the types of therapies and services autistic people are subjected to and how those services are carried out. Health insurance providers, both public and private, also have an obligation to ensure that the services they cover are actually helpful, rather than hurtful, to autistic people. These changes must be carried out at a systemic level to ensure equal access to truly ethical, helpful services for all autistic people who pursue them. We do not want to exacerbate the current system where only autistic people and families with the money, time, and energy to pursue and fight for non-abusive, truly helpful services receive them. All autistic people, regardless of their financial situation, cultural background, and level of support needs, deserve high-quality, ethical services – no matter what.

We emphasize that more, and better-quality research, is needed. Our work researching and writing this paper was plagued by the low-quality research literature available, research that subjected autistic people to unethical interventions against their will, and research whose results could not be replicated in subsequent trials. The vast majority of scholarly research into autism interventions excludes autistic people from its research team. We encourage researchers to adopt a framework of community-based participatory research (CBPR) and to ground their research ethics in the writings of autistic people, scholarly or not, on the ethics of autism intervention. Creating truly ethical, meaningful, and helpful autism therapies and services cannot be possible without the involvement of autistic people of all ages and backgrounds at all levels of intervention development and testing.

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