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Don't Make Me Say "I Love You": A Dive into the Complicated Discourse Surrounding Applied Behavior Analysis

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by

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Dedicated to the Autistic Community

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This project would not have been possible without the help of a number of people, both online and in person, who educated, encouraged, and supported me throughout the past year. To my advisor, Sarah Dunphy-Lelii: thank you for always challenging me with questions I never would have thought of, helping me to believe in myself, sitting through my endless rants, and making our advising meetings one of my favorite parts of every week. To my boyfriend, Dylan Lalanne-Perkins, thank you for *also* listening to my endless rants and for making me laugh even when I was overwhelmed. And to my autistic friends, family, and all the autistic creators on social media who have taken the time to share your experience and knowledge with the world, none of this would have been possible without you, so a huge thank you to all of you.

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Abstract

This paper investigates the empirical evidence and discourse surrounding a popular therapy for Autism Spectrum Disorder (ASD) known as Applied Behavior Analysis (ABA). While studies over the past 60 years have shown ABA to be a highly effective therapy for decreasing unwanted behaviors and increasing compliance in people with autism, many autistic adults have expressed that the therapy had long-term harmful effects on their mental health and wellbeing. Using a combination of works written by autistic voices and psychological studies, I argue for a reconsideration of the benefits and costs of ABA, and emphasize the importance of including actual autistic people in the development of further research and treatments.

Keywords: autism, applied behavioral analysis, neurodivergence, disability

Disclaimer

First, as someone who is not a member of the community I am researching and writing about, I think it is of utmost importance to acknowledge the privilege I hold and to thank all of the advocates and members of the autistic community for educating me and allowing me into their world. I also want to emphasize that this project is not meant to speak for or over autistic people, but rather to recognize and uplift their work and combine it with the empirical research done in the field.

The project you are about to read is unique in that it combines a number of disciplines and fields and also is purposefully drawn from *both* empirical works as well as personal experiences, blogs, and other pieces of digital media. While this may not be the most traditional way to compose a thesis, I felt it was crucial to the reader's understanding to include a large and diverse amount of actual first hand accounts of what it is like to be autistic, as well as consider these issues from the perspective of those who they affect directly. I encourage you as a reader to open your mind to the idea of treating the autistic voices included here with equal, if not more, seriousness and respect as the researchers mentioned.

Third, you may find that some of the language in this paper is unfamiliar and different from what you may have heard in the past. This is purposeful, as I have researched very carefully into what is preferred by those in the autistic community, and I have included footnotes as a way of clarifying any language that may be new or confusing for those who have not been exposed to it before.

Finally, I want to express that this research has been incredibly important in my own understanding of the ways I promote ableism in my daily life and my journey to reduce this unconscious bias and harm. I hope that it enlightens others to explore their own relationship with disability, neurodivergence, and dependence.

Content Warning: Descriptions of physical, sexual, and mental abuse.

Abbreviations

AAC Augmentative and Alternative Communication

ABA Applied Behavior/Behavioral Analysis

ADHD Attention Deficit Hyperactivity Disorder

ASL American Sign Language

BCaBA Board Certified Assistant Behavior Analyst

BCBA Board Certified Behavior Analyst

BCBA-D Board Certified Behavior Analyst-Doctoral

COI Conflict of Interest

DSM Diagnostic and Statistical Manual of Mental Disorders

DTT Discrete Trial Training

EIBI Early Intensive Behavioral Intervention

ESDM Early Start Denver Model

ECT Electro-Convulsive Therapy

GED Gradual Electronic Decelerator

NET Natural Environment Teaching

NLP Natural Language Paradigm

PECS Picture Exchange Communication System

PRT Pivotal Response Training

RBT Registered Behavior Technician

TOM Theory of Mind

VB Verbal Behavior Approach

Introduction

This project began because I made a big mistake. In the summer of 2021, I started a job as a substitute teacher at a school I had heard about from my peers at college, after doing exactly zero minutes of research on it. What I had been told was that the school was for children with Autism Spectrum Disorder (ASD), and as a psychology major with an interest in child development and experience working with children, I felt I knewwhat I was getting into.

On my first day, I showed up wearing a flowery, purple dress and a huge, nervous smile. I was directed down a hall into a middle school-aged classroom with about four other teachers and ten or so students. Immediately, I noticed that I was sorely overdressed, and was told that in the future it would be important to wear clothes I could move better in and not to wear any jewelry, as I would likely have to chase and occasionally restrain kids in the classroom. This was my first surprise, and felt strange to me, but I figured they were the experts and surely this was just an extra precaution. Overall, the first day went fairly well. I got to spend one-on-one time with each of the kids, play games, and give them candy. I wasn't required to instruct them in any way, and there were lots of other teachers around to answer my questions.

The second day, I was placed in one of the preschool classrooms. Because I had the most experience with this age group, I immediately bonded with a number of the children and, despite the fact that the rest of the "substitutes" were meant to switch classrooms each day depending on who was missing staff, I was asked by my supervisor to remain in that same classroom for the rest of the summer. I felt quite special being noticed in this way, and shortly after was also rewarded with a number of responsibilities. This was likely in part due to the fact that the school

was still incredibly understaffed due to the COVID-19 pandemic, but nonetheless I took it in stride and tried to learn as much as I could in as short a time as possible.

Within the first few weeks, I learned that a big part of the job was just trying to keep the kids in their seats. They kept running off or getting restless, and it was my job to entertain them, and if that didn't work, sit behind them to physically block them from pushing their chair out and walking away. This made me feel uneasy, especially since my previous experience in preschools mostly consisted of classrooms were children were allowed to play freely and move around the room rather than sitting at desks all day, but I assumed part of it was too keep them safe from getting sick (once again COVID-19 was very present during this time).

Within the first month, I was put in charge of working on fine motor skills with all the preschoolers in my classroom. I was given a binder full of information and sheets to track data, and a short, rushed training by our head teacher on the basics of what I was to do. I felt sorely underqualified for the role, especially since I didn't even know what the name of this education style was. After some Googling, I discovered it was an educational therapy designed for kids with autism called Applied Behavioral Analysis or ABA for short. I had never heard of it, but there were tons of studies proving its effectiveness, so I figured it must be pretty good.

Around the same time I started the job, I also downloaded Tik-Tok, a social media app for making videos that at first seemed pretty pointless. It was mostly just a lot of short videos of people dancing and lip-syncing to songs. But its algorithm showed you new things based on what you liked previously, and I quickly discovered that there were all kinds of people on the app, talking about pretty much everything you could think of.

And then one day, a video about ABA appeared on my feed, and I froze. It was made by an autistic creator about the same age as me, and they quickly outlined all the reasons why ABA therapy was a form of abuse. While I wanted to be surprised, I also recognized that something inside of me knew from the beginning that what I was involved in wasn't right. These kids who I loved so much, who I had spent the whole summer supposedly "helping", actually might not be benefiting from what I was doing at all. In fact, a lot of the things we were doing were probably making them feel worse.

When I told my supervisor it was time for me to leave, they offered me a raise and a full time position. It was the first full time job I have ever been offered, and it felt incredibly wrong. I wasn't qualified for this position at all, I had no background in education, and I had only been working there a few months. I politely declined.

After realizing what a huge mistake I had made and the harm I had caused to those children, I felt discouraged and angry at myself. But I also realized that I was not the only one making this mistake, and that there were lots of educated people who truly believed that this was the right way to do things. The more I looked into it online, the more I realized that the voices of autistic people were being stifled. They did not have a say when it came to the development and implementation of this therapy, and the problem was much bigger than I had thought. ABA was everywhere.

The reality is, this problem is not about me or my mistake. While it's important for me to own the fact that what I did was wrong, it's more important that other people know not to make the same choices I did. The world needs to know both sides of the story.

Applied Behavior Analysis

"…applied behavior analysis (ABA)…focuses on solving problems of social importance using the principles and procedures of behavior analysis," (Fisher et al., 2021, p. 3).

What is ABA?

Applied Behavioral Analysis, also sometimes called Applied Behavior Analysis or "ABA", is the most popular therapy for Autism Spectrum Disorder (ASD) in the United States. It is supported by a number of large organizations related to autism including Autism Speaks, Autism Society of America, and The Autism Research Institute. Many praise ABA as a " cure" for autism and you can find thousands of testimonies from family members of autistic people[1] describing how the therapy completely changed their loved one for the better. For example, the following testimonial from a parent that sent their child with autism to The Lovaas Center, a well known treatment facility for autism, named after the creator of ABA:

> Nate was diagnosed severely autistic at age 2, and we started ABA right away. Now he's in the 5th grade and attending school with all the 'typical' kids and without an aide. I like to say 'Sure, he isn't typical. He's downright remarkable!' He's exceptionally bright, gets straight A's, and has a heart the size of Texas. And I wish my other two kids were as well behaved as Nate (The Lovaas Center, 2022).

Applied Behavior Analysis can come in a variety of different forms and names, and the definition can vary depending on who is implementing it. A few examples of the various models of ABA include the Developmental Social-Pragmatic Model (DSP), Early Start Denver Model, Learning Experiences: An Alternative Program for Preschoolers (LEAP), Reciprocal Imitation Training combined with DSP and incidental teaching, Floortime, parent training based ABA, and

[1] In this paper, I will be using person first and identity first language interchangeably out of respect for the members of the autistic community who might prefer one or the other (Haelle, 2019). When interacting with autistic people individually, it is encouraged that you ask what terms they prefer you use, rather than just assuming.

many more (Smith & Iadarola, 2015). We will learn more about the most common types of ABA and how they work in the next section.

For the purposes of this paper, we will be utilizing the definition outlined in the official *Handbook of Applied Behavior Analysis* which does a good job of distinguishing ABA from other behavioral sciences, "Behavior analysis is a discipline with three primary branches…(1) behaviorism, which focuses on the worldview or philosophy of behavior analysis; (2) the experimental analysis of behavior, which focuses on identifying and analyzing the basic principles and processes that explain behavior; and (3) applied behavior analysis (ABA), which focuses on solving problems of social importance using the principles and procedures of behavior analysis," (Fisher et al., 2021, p. 3).

In other words, while ABA is a part of the larger field of behavior analysis, it differs from the other branches in that its goal is to solve problems in behavior relating to the social world. If you took an introductory course in psychology, you may be familiar with B.F. Skinner, a famous behaviorist who conducted experiments that involved manipulating the behavior of people and animals using reinforcement and punishment. While ABA is related to behaviorism, it is set apart from the work Skinner did in that it is designed to target *social* behaviors, and while it can be used in other instances, it's almost exclusively performed on children with autism, and very occasionally those with other developmental or intellectual abilities.

How Does it Work?

Under the larger umbrella of ABA, a number of specific approaches exist, all of which seek to modify behaviors which relate to the social world. However, each approach is different in what is specifically being targeted and how, and often multiple approaches are used in tandem

with one another. All types of ABA involve using the natural environment and the ways in which people interact as an opportunity to alter someone's behavior through a structured reward (and sometimes punishment) system.

Let's use an example: one behavior one might want to work on is teaching a child to sit in a chair. At first, the child might be running around the room, distracted, and not at all interested in sitting in the chair. The therapist, usually a Registered Behavior Technician (RBT), would first give some sort of prompt. In this case, it would be to give the direction to the child to sit down. They might do this in a number of ways: speaking the words, modeling the behavior themselves, showing the child a picture of someone sitting down, or using American Sign Language (ASL) to ask the child to sit down. The child might not listen or understand what is being asked at first. The RBTs are trained to ignore the child's unwanted behaviors, give them a more intensive prompt such as helping the child to their seat, or persist with the original command and not react to what the child is doing until they comply. The therapist may need to break up the behavior into smaller parts, such as getting the child to sit near the chair and rewarding them for that, and then getting them to stand above the chair and rewarding them for *that*, before finally sitting in the chair. This process where the therapist slowly guides the behavior of the child towards the desired outcome is called shaping. When the child is finally able to sit, they will receive a reinforcer from the therapist.

A reinforcer is something given to the child that associates the wanted behavior with a positive outcome. It could be as simple as a "Good job!", or it might be in the form of a food the child enjoys such as a candy or a small piece of cookie. Other times it could be a toy the child likes, a song, a hug, or a video. The likes and dislikes of the child are usually established before

training begins, and are used to associate positive feelings towards the therapist, which is called "pairing". This is a secondary goal of the therapy which allows it to run more smoothly: once the child has established trust or some kind of bond with the therapist, they are more likely to comply.

When the therapist asks the child to sit another time, they might try to fade the prompt slightly, such as simply gesturing to the chair instead of telling them to sit down. If that doesn't work, they start again from the beginning.

This form of therapy allows the child to experience "errorless teaching", meaning the teacher never has to explicitly tell the child that they are incorrect. While the child is making constant errors, to voice those mistakes would be discouraging, "No you are sitting on the floor, not the chair. No, you are standing on the chair. No, you need to sit up, your head can't be between your legs. No, you have to sit forward." This kind of dialogue would be exhausting and unnecessary for the child to have to deal with. Instead, the therapist will attempt to ignore all of these "incorrect" behaviors during the teaching process, because they also don't want to accidentally reinforce the behavior the child is exhibiting. The child might think, "I am standing on the chair, and they're talking to me. That must mean I am doing the right thing!" They might also be looking to get a reaction out of the therapist, or find it entertaining to see them say no repeatedly (as all children sometimes do). So the therapist avoids any behaviors such as these which might encourage the child to continue doing something against the therapist's requests.

When trying to get rid of certain unwanted behaviors, such as running around instead of sitting down, ABA seeks to analyze all of the surrounding factors including what is happening before and after the behavior (Kirkham, 2017). In other words, in order to "extinguish" a

behavior or keep it from continuing, the therapist will first look at what is causing the behavior (the antecedent), what the behavior actually is, and then what happens after the behavior has been performed (the consequence). Part of the goal of ABA is to extinguish certain behaviors that are not deemed socially beneficial in some way, such as self harming or aggressive behaviors, and also to teach and reinforce those that are positive to the social experience, such as communication.

For example: a child is hungry (antecedent), so they whine (behavior) until their parent gives in and feeds them (consequence). This is accidentally reinforcing the idea that whining will get the child food. If the therapist wanted to discourage the child from whining, they might change the consequence of the behavior: instead of reinforcing the whining, they will wait until the child stops and asks politely for food, and then reinforce that behavior instead by providing a snack. It is generally much easier to control the consequence of a behavior than the antecedent, though the latter is occasionally also possible. If, for example, you realize that a child is crying every time they have to put on shoes because their shoes are too small, you can extinguish the behavior by simply buying the child a new pair of shoes. It gets to be more complicated, however, if the child is unable to communicate what is bothering them, or if the reason for the behavior is less transparent.

When it comes to the various types of ABA, there are an infuriating number of acronyms to sift through, so let's take a moment to swim in the alphabet soup as we learn some of the most popular subsets of the therapy. Since an early start can lead to better results, you will often hear practitioners stressing the need for Early Intensive Behavioral Intervention or "EIBI". This simply refers to any ABA which is implemented in young (usually preschool aged) children and

is intensive, meaning it is performed for many hours (up to 40) every week. There are various approaches that can be implemented, including the Discrete Trial Teaching[2] approach or "DTT". There is also Natural Environment Teaching (NET), Verbal Behavior (VB), Pivotal Response Teaching (PRT), Early Start Denver Model (ESDM), and many more (Gaunt & Karpel, 2017).

Discrete Trial Teaching

Discrete Trial Teaching or DTT focuses on teaching through repetition, sequenced instruction (breaking up large tasks into smaller pieces and then chaining them together in a sequence), task variation, (changing up the tasks frequently in order to keep the child's interest) interspersal (periodically adding in a task that the child has already mastered to boost confidence), and errorless teaching. It is generally fast paced so that the child can get in as many learning opportunities as possible. An example of DTT would look like this: a teacher and student sit at a table together and the teacher gives the child a direction, such as "touch the red card" (often with young children and those who have limited language skills, flashcards with pictures on them are used as an early form of testing the child's knowledge). If the child gets it wrong, the teacher may correct the child by using hand-over-hand (taking the child's hands in theirs and putting it on the red card) then saying "red". In order to avoid the child feeling like they have failed, the teacher will then quickly ask the child to do something else they have already mastered, such as imitating the teacher clapping. The child is reinforced for their correct behavior, and then they go back and try for the harder task again. This is task interspersal: the harder tasks are quickly followed by easier ones so the child doesn't dwell on their mistakes.

[2] A number of these approaches, including DTT, are often referred to as "training" and "teaching" interchangeably. However, due to the association between training and animals and the history of dehumanization of people with autism and other disabilities, I will be using the word teaching (Millman, 2019).

Additionally, the trials are usually identical at first (always the same red card and the same question) which is good for making sure the child associates this specific word with this specific task and will be able to retain it. DTT is very useful for skills that require repetition and aren't very interesting or motivating for the child to learn. It is also good for tacting (labeling or naming objects or people), imitation, and receptive skills (Weiss, 2005). However, a major downfall of the approach is that it is not generalizable, meaning it often doesn't carry over into the real world. Though a child might be able to identify a red flashcard in the classroom when asked in a specific way, they might still struggle to label a fire truck as red when taking a walk with their family (Granpeesheh et al, 2009).

Verbal Behavior

The Verbal Behavior or VB approach's name is misleading in that many people assume it is used only for language development and only on children who are non-speaking. However, it is an all encompassing approach that uses other methods of ABA while also focusing specifically on language development. It has been shown to increase communication skills in children and adults who may have no language, some, or a good amount but are still struggling to actually make that leap into the realm of conversation. Based on B.F. Skinner's book, *Verbal Behavior*, VB centers around the idea that language is a behavior which can be shaped and modified over time. It begins by assessing the individual using the Assessment of Basic Language and Learning Skills (ABLLS). Next, the therapist will "pair" themselves with the child (just like in DTT) by providing objects or activities the child enjoys and engaging with them (Barbera, 2007).

At this point, the learning can begin. The therapist can begin to withhold the items which the child wants, motivating the child to request them through some form of communication

which is called a “mand”. A mand may start as a gesture, such as a reach or a point towards the object. While it may seem odd to reinforce such a simple form of communication, it is crucial to reduce the likelihood of less desirable behaviors being used to communicate (such as a tantrum or aggression). Once the child has mastered pointing, they might move on to sign language, or a Picture Exchange Communication System (PECS), an Augmentative and Alternative Communication (AAC) device, a communication board, or even spoken word. This quote sums up the strengths of the therapy well:

> It [VB approach] allows for the child to lead the way to his own learning by using things that he finds motivating. The child’s communication abilities are clearly broken down into functional slices, making his language easy to assess and program for. Language and behavior are treated simultaneously as two sides of the same coin (Barbera, 2007).

However, problems may arise from using things the child enjoys to get them to learn (especially if it is a food or toy which is not related to the lesson itself), even if it is for the sake of improving their ability to communicate their needs. Additionally, it leans on other approaches to address aspects which are not language centered.

Naturalistic Teaching

Naturalistic Teaching is an umbrella term for those approaches to ABA in which the learner initiates and the teacher tries to spark the learners interest as much as possible (similar to VB). Under this larger field of Naturalistic Teaching in ABA sits Pivotal Response Teaching (PRT), milieu teaching, and incidental teaching. There is a looser structure and a larger emphasis on *intrinsically* motivating materials and the child guides the instruction and language. Many naturalistic approaches look a lot more play based and require less time sitting at a desk and going over flashcards.

For example, using a naturalistic approach, the therapist may allow the child to choose a toy as they would in any other context, and then use that as an opportunity for learning. If the child chose to play with trains, they could practice language surrounding trains, or taking turns, or they could sit by the box and get the child to mand for more pieces of the train track. Incidental teaching is similar in that it is based on specific events (incidents) that occur naturally and can be used as teachable moments. It can be implemented on its own or within any of the other ABA styles.

Pivotal Response Teaching (previously called the Natural Language Paradigm or NLP) targets important (pivotal) aspects of the child's development instead of focusing on one specific behavior. These areas include motivation, response to multiple cues, self-management, and initiation of social interactions (Koegel et. al, 1999).

Milieu teaching is the practice of arranging a child's environment in a way which encourages them towards a specific behavior. While this is a practice which can be used in all forms of ABA and teaching in general, it can also be effective when used on its own (Christensen-Sandfort & Whinnery, 2011).

Why Do People Love It?

Applied Behavioral Analysis has been empirically proven to help children with autism with a number of challenges the disorder can present, including poor performance on IQ tests and self harming or aggressive behaviors (Lovaas, 1987). Additionally, it has been shown to help children with speech delays to learn to communicate, keep children from performing restrictive or repetitive behaviors, and increase overall compliance (Yu et al., 2020). Many families attest

that one of the biggest benefits of ABA is that it can help their child become more “normal” and fit in better with their peers (The Lovaas Center, 2020).

A benefit of all types of ABA is that it is a flexible therapy that can be provided in a variety of environments, including at home or in school. In fact, there are a number of schools that were created completely for the purpose of educating children with autism (such as the Center for Spectrum Services, Anderson Center for Autism, and Judge Rotenberg Educational Center and over 100 others in the United States alone) which allow for ABA to be administered throughout the school day by the special educator as well as other trained assistants in the classroom. This can be beneficial for children not only because they are receiving extra services, but also because they are able to be around other kids with autism, which often leads to a decrease in bullying and isolation (Dillenburger et al., 2012).

If families would prefer to send their child to mainstream school, behavioral technicians can also provide the same services during school hours, accompanying students to their classes and providing extra support (Kersey, 2017).

In the home, ABA can be administered by Registered Behavioral Technicians (RBTs) one-on-one with the opportunity for parent involvement, as well as a flexible schedule. It also opens up the opportunity to practice skills in the environment where a child feels most safe. However, a downside is that the child is not exposed to other children with autism and also gets less experience with certified special educators (Dillenburger et al., 2012).

In summary, not only is ABA backed up by more studies than any other current therapies available for autism, it also comes in a variety of forms, and has a long history. What exactly

about ABA makes it the right fit for autism specifically? In order to understand that, it is important to look at the characteristics of autism and the challenges it presents in daily life.

Autism

"Autism is a lifelong developmental disability which affects how people communicate and interact with the world," (National Autistic Society of the United Kingdom, 2021).

What is Autism?

Autism is diagnosed on the basis of "disordered social interactions, delayed or disordered communication, and restriction in range of interests and activities," (Jacobson et al., 1998). In order to receive an autism diagnosis according to the DSM-V, a person must experience "persistent deficits in social communication and social interaction across multiple contexts," as well as exhibit, "Restricted, repetitive patterns of behavior, interests, or activities." Additionally, these symptoms must be present in the "early developmental period" (childhood) and cannot be better explained by an intellectual disability or developmental delay.

But what does all that actually mean? Autistic people have come up with more simple terms for these characteristics that also help better explain their functions. For example, restricted and repetitive patterns of behavior could be translated to "self-stimulation" or "stimming". Stimming is not specific to autism, and can be performed in a variety of ways including hand flapping, biting nails, making sounds, picking at skin, jumping, and more. Autistic people do tend to stim more often than others, and use it to self-regulate if an environment is overstimulating. Additionally, it has been found to reduce stress and anxiety, and be an overall pleasurable experience for autistic people (Beardon, 2021).

Similarly, "restricted interests" can be translated to mean "special interests", where a person with autism might have a very intense interest in a certain subject, field, or object.

Oftentimes, autistic people are experts on their special interest, and spend many of their waking hours thinking about it and engaging with it in some way. A special interest can be based in anything, from trains to wood working to a specific television show or book. Many autistic people report that talking about their special interest gives them a lot of joy, and it is sometimes difficult to keep from bringing it up in conversation or talk about anything else, which is what can make the interest "restricted" and present problems in the social world (Beardon, 2021).

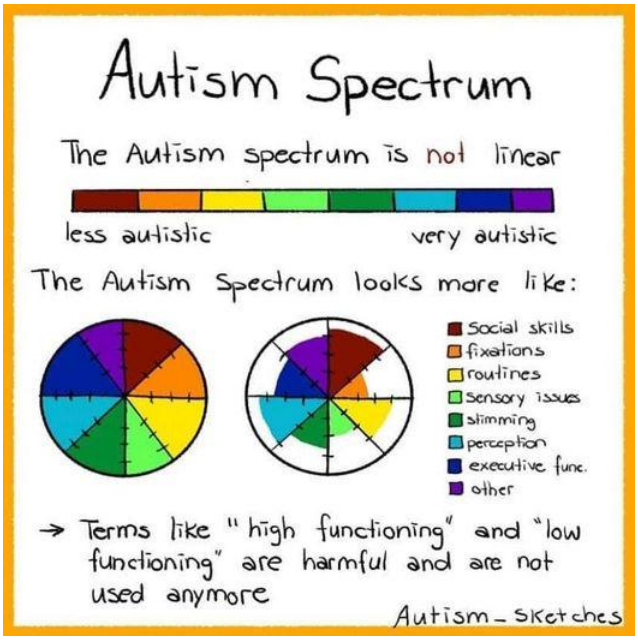
The last important piece of an ASD diagnosis is "disordered social interactions". While this can mean language impairments or delays (where children may not learn to speak using words until five and six years old, or possibly not at all), only 25% to 30% of autistic people are non or minimally speaking (Lebenhagen, 2021).[3] For the rest, social communication may be inhibited because of a misunderstanding of social cues, norms, or intentions. A person with autism might have a robust vocabulary, but still struggle to understand what the appropriate thing to say is in a given context. Additionally, autistic people often report feeling confused by certain forms of communication which require a complex understanding of the speaker's affect when speaking, such as jokes or sarcasm (Beardon, 2021).

Some researchers believe this kind of "disordered social interaction" (Jacobson et al., 1998) may be due to a lack of theory of mind (ToM) which has to do with one person's understanding of another's differing perspective, beliefs, and desires. There has been some debate on this topic as well as its relation to empathy, "ToM which has been postulated to be a

[3] In this paper, I will be using the terms "non-speaking" instead of "nonverbal" due to the fact that some members of that community have expressed a stigma around the term nonverbal. Those who are non-speaking often have other modes of communicating including AAC and sign language.
"I like to call myself nonspeaking because I can communicate by spelling words instead of speaking. Nonverbal implies I do not understand words. How can I communicate with words if I am nonverbal?" - Philip Reyes, a non-speaking autistic individual

core deficit within autistic people, is not an impairment that resides within autistic people but rather a mutual difficulty relating, as neurotypical[4] people also face unacknowledged challenges understanding the minds of autistic people," (Gillespie-Lynch et al., 2017). This has been called the "double-empathy problem" and asserts that people with autism may struggle to understand the minds of neurotypical individuals, but the same is also true the other way around: neurotypical people *also* struggle to understand what autistic people are thinking.

It is important to note that autism does, in fact, exist on a spectrum, but not in the way many people assume. Instead of existing on a line from "low functioning" to "high functioning," which are labels that many may still use today but can still be incredibly harmful to a large portion of the autistic community (Spectrum News, 2020), it is more of a circle where some areas may require more support than others. Below is an illustration created by an autistic person which shows the importance of this difference.



(autism_sketches, 2020).

[4] "Neurotypical" is a term used to describe those with typical developmental, intellectual, and cognitive abilities. On the flip side, those with atypical developmental, intellectual, and cognitive abilities (such as autism or ADHD) are often referred to as "neurodivergent" (Beardon, 2021).

Someone might have very high support needs when it comes to, say, sensory stimulation, but need very little support when it comes to social interactions. On the other hand, someone might need to rely on AAC to communicate, but be completely capable of entering a loud and bright space without experiencing sensory overload. It is important to not make assumptions about the support needs of any individual, regardless of how they appear or previous interactions you may have had with other autistic people. This is especially important to note for non-speaking people: just because someone uses a different mode of communication does not mean they are intellectually any less capable than their speaking peers.

Causes and Prevalence

No one knows what causes autism exactly, though some believe it has a root in genetics (Rutter et. al, 2000). In the past, people have attributed autism to all kinds of things, including vaccines (Wakefield, 1998), mothers not being attentive enough, poor diet, or even mercury poisoning (Silberman 2015). However, there is no evidence for most of these claims, even after extensive research. In the past 20 years, billions of dollars have been spent on autism research, including a fifty million dollar research project funded by Autism Speaks which mapped the genomes of people with autism and their families. Their findings were that there is no single gene which can account for autism, though this is not to say that it might not still be genetic (Silberman, 2015). Additionally, the famous study which was used as evidence for a causal relationship between vaccines and autism (Wakefield et. al, 1998) was not even originally designed to look at that relationship, and has since been disproven numerous times (DeStafano, 2007; Luke et. al, 2014).

The prevalence of autism has increased in recent years, with a diagnosis of autism being predicted to affect 1 in 150 children in the United States in the year 2000 to 1 in 68 in the year 2016 (CDC, 2021). However, it is difficult to say whether this is an actual increase, or is simply because our diagnostic tools have changed. Additionally, most past research has shown that autism is more common in cisgender boys (DSM-III, 1980), but more recent studies show that autism may present itself very differently in cisgender girls, leaving them undiagnosed until much later in life, if at all (Dworzinski, 2012). Lower rates of diagnosis lead to less support and therefore higher rates of internalized problems such as anxiety and depression (Young et al, 2018).

It is important to note that there are almost no studies on the rates of autism in transgender and non-binary people at all, meaning that when claims are made about the differences in the way autism presents itself in different genders, they are talking about cisgender people only. This is a problem that needs to be addressed and researched more thoroughly, and until then, it is important to use the correct language when talking about the results of existing research. It is especially disturbing that more work has not been done on this subject considering that autistic people are more likely to identify as LGBTQ+ than their neurotypical peers (Sarris, 2020; George & Stokes, 2020).

In general, autism research has historically consisted of mostly cisgender men and boys as participants. In a meta-analysis of 392 articles on autism, 80% of the participants were cisgender men, and only 5% analyzed any variables that considered gender or sex (Young et al). Additionally, the diagnostic tools currently available for autism are designed to look at

stereotypically “masculine” interests and behaviors: examples of special interests given to clinicians to look out for include topics such as trains or sports.

Additionally, educators and diagnosticians are more likely to notice behaviors which are outwardly disruptive, which is more common in cisgender men than cisgender women, who may have more internalized symptoms (Rynkiewicz et al, 2020). For example, someone with more externalized symptoms of ASD may display aggression towards peers or resist following instructions, whereas someone with more internalized symptoms may be more socially withdrawn or quiet.

Comorbidities can also pose a challenge in regards to diagnosing cisgender women. Multiple studies have found evidence that suggests comorbidities between Bipolar Disorder, tic disorders, and Attention Deficit Hyperactivity Disorder (ADHD) and autism. Mood disorders are more likely to be diagnosed in cisgender women, and the specific comorbidity of ADHD and autism has also been found to be higher. This could cause the practitioner to ignore autistic traits because they attribute them to these other disorders, but in the case of ADHD it could also mean that the two disorders are working against each other. People with ADHD and autism have reported the symptoms of the two “balancing each other out” at times: the autistic side’s need for order and routine might be dampened by the ADHD side’s lack of ability to maintain focus (Rynkiewicz et al, 2020). Cisgender girls who struggle socially may be diagnosed with bipolar disorder simply because therapists have a bias towards it being more common within that group, and don’t even think to consider autism as a possibility.

Finally, a big reason why autism is under-diagnosed in cisgender women is the fact that they exhibit higher rates of masking or camouflaging their symptoms. “This camouflage can be

of two types: active (use of strategies to mask their difficulties, copying peers, and overcoming social communication deficits typical of ASD to 'seem normal' and maintain friendships) or passive (spontaneous mimicking of behavior and accents)," (Young et al., 2018). Hiding symptoms will, of course, lead to later diagnosis or none at all.

You may be wondering why exactly it is a problem that autism is being underdiagnosed, if someone is able to hide their symptoms in the first place. The answer is, masking takes *work*, whether it's active or passive, conscious or unconscious. The symptoms aren't simply gone just because they are hidden, and many people report feeling exhausted, depressed, or anxious during or after long periods of masking (Gould, 2017). Hiding yourself and your natural behaviors is not a positive feeling, and it often takes years to unlearn. This demonstrates just how important it is to change the way we are diagnosing autism to be more inclusive and ensure everyone receives the support they need.

Challenges

Autism can pose some unique challenges in communication and social skills. A common trait of autism is the occurrence of "meltdowns" and "breakdowns" (Ryan, 2010). These tend to happen when an autistic person is feeling overstimulated or is experiencing extreme levels of stress. A breakdown is a more passive reaction, such as feeling mentally, emotionally, or physically exhausted. Whereas a meltdown consists of, "behaviors that appear…to be out of context…and may be destructive (to oneself or others or the environment)," (Beardon, 2017, p 44). This includes behaviors such as self harm, aggression, yelling, and crying. Often in children, meltdowns are mistaken for "tantrums" that neurotypical children of the same age may also have and can often maintain control over. Meltdowns, however, are out of the autistic person's control,

and making the assumption that they are purposeful can be very harmful. Additionally, meltdowns might occur significantly after the overstimulating event, especially when the individual is masking, which can make it harder to attribute the reaction to the exact cause.

Because autism is an invisible disability (meaning there are no physical features which would allow others to know that the individual is disabled just by looking at them), if a child with autism is experiencing a meltdown in a public place, they are treated with the same level of judgement as a neurotypical child would experience. Often, people with autism are judged at the exact time when they could really use support. One parent of a child with autism said, "When people stop and stare in the street or he is having a tantrum and everybody is looking at you thinking, 'Can't you control that child?' and you just, you get really upset because it is not his fault that he is being like that," (Ryan, 2010, p 872). As with this example, sometimes the stigma around certain behaviors an autistic child exhibits presents more problems for the family than the behavior itself.

Unfortunately, there have been a number of misconceptions about autism since its naming, which has created a complicated history for the individuals who receive this diagnosis.

History of Autism

The word autism comes from the Greek word "autos" which means "self". While autism has likely existed throughout history, it has only recently acquired a name. In the past, children with what we know today are characteristics of autism were believed to have an early form of schizophrenia. Before the twentieth century, children with this "childhood schizophrenia" were often destined to spend their lives in institutions (Kirkham, 2017) (DSM-II, 1964).

> The first account of "childhood schizophrenia" in America, published in 1933 by Howard Potter of the New York Psychiatric Institute, outlined a set of behaviors that overlapped closely with later descriptions of

> autism including a "defect in emotional rapport," disturbances of language development, "diminution of affect," and "bizarre behavior with a tendency toward preservation and stereotypy (Silberman, 2015).

Before the 1900s, people with mental illness or disabilities were often believed to be "incurable", destined to spend their days in prison or in the care of their families. However, everything changed during the rise of Freudian psychoanalysis. Suddenly, there was a new understanding that it might be possible to treat these patients and see them become more independent, keeping them out of institutions which could save lives, money, and keep families together. One of the first people to work with disabled children in this new age of psychology was a man living in Vienna named Hans Asperger.

You probably know Asperger from the short lived "Asperger's Syndrome", which entered the Diagnostic and Statistical Manual of Mental Disorders (DSM) IV in 1994 and exited in the most recent 2013 edition, DSM V. However, Asperger never named a syndrome after himself, as he wasn't even alive when it came to be. His work was rediscovered after his death, and the syndrome was named after him because he focused his work mainly on autistic children with low support needs who had special gifts (which is the exact population which later fell into the category of Asperger's Syndrome).

Together, Asperger and his colleagues Erwin Lazar and Anni Weiss created a therapeutic education center for children. "Instead of viewing the children as 'patients,' he [Asperger] saw them as future bakers, barbers, farmers, professors, and engineers," (Silberman, 2015, p 85). Asperger's team believed it was necessary to look at the entire child: to talk, play with, and observe them in their daily life in order to fully understand their experience and therefore provide them with the tools they need to reach their full potential. Additionally, unlike today when a lot of behaviors are classified as "good" or "bad" based on whether or not they pose

challenges to people around them, Asperger and his team looked at how the behaviors were affecting the *child*. An observer of Asperger's ward once commented that the way it was run was unique in that, "'Fundamentally there appears to be no special interest in the differences between normal and abnormal…as it is felt that theoretically this is unclear, and practically it is of no great importance,'" (Silberman, 2015, p 88). In other words, Asperger's program was ahead of its time in that it focused less on what was considered to be "abnormal" or a deficit in the child and more on their strengths and abilities.

Unfortunately, Asperger's work on autism, which he called *autistichen psychopathen* (autistic psychopathy) took place during an incredibly tumultuous and dangerous time in history for disabled people: the rise of Hitler. Shortly after the beginning of World War II, Hitler created a program called Aktion T-4 which set out to murder any child who may have some sort of heritable disability. Although Asperger's surviving relatives assert that he was never a member of the Nazi party, it is known that he, as a pedatriacan, knowingly referred children to the Aktion T-4 program to be killed based on whether he thought they were "educable" or not (Yeginsu, 2018). Today, much of the autism community avoids the term Asperger Syndrome, due to this complicated history, the fact that it is no longer an official disorder, and also because the existence of the disorder helped to divide autistic people from each other based on their support needs. However, some people may still choose to identify with the term, and valued the division between what was thought to be two separate disorders. That choice is ultimately up to them and their own relationship with being on the spectrum (Sparrow & Silberman, 2018).

At the same time in the United States, a man named Leo Kanner was working with the same population of children. Kanner named the characteristics this group shared "infantile

autism" and believed it to be very rare. While he was aware of Asperger's work, he discredited it. This is especially ironic considering he actually ended up working with one of Asperger's former colleagues: Weiss.

Unfortunately, Kanner's ideas about autism were flawed as well, "Where Asperger saw threads of genius and stability inextricably intertwined in his patients' family histories-testifying to the complex genetic roots of their condition and the 'social value of this personality type,' as he put it-Kanner saw the shadow of the sinister figure that would become infamous in popular culture as the 'refrigerator mother,'" (Silberman, 2015, p 188). This mindset that some mothers (especially those who worked) were considered to be cold and unloving to their children and therefore were the cause of their children's autism led to a lot of problems. Researchers began looking in all the wrong places, mothers were afraid to seek help for their children, and children were removed from their homes based on the false idea that the parents were inhibiting their child's growth.

Though things did improve for many people after the war ended, it didn't for everyone. In the 1950s, a new face took the stage: Bruno Bettelheim. A Jewish survivor of the concentration camps, Bettelheim certainly wasn't a believer in eugenics, but he also wasn't tender towards the children he worked with. "Former student Ronald Angres, diagnosed as autistic by Bettelheim, wrote that in his twelve years at the school [which Bettelheim created], he lived in abject, animal terror of hearing the squeak of his [Bettelheim's] crepe-soled shoes in the dorms,'" (Silberman, 2015). Bettelheim went on to be a famous researcher and writer in the field of autism, but his school and others like it continued to terrorize the very children he was supposed to be helping

by separating them from their families, using inhumane forms of "treatment", placing them in isolation for extreme periods of time, and much more.

Just a few of the so called "treatments" autistic children were subjected to include electro convulsive therapy (ECT) (which is still being practiced today, more on that later), antipsychotics (which led to irreversible tic disorders), hallucinogens, tranquilizers, and months of complete isolation (Silberman, 2015).

By the 1970s, researchers were at least starting to understand that autism was a condition with symptoms that are onset from birth (Kirkham, 2017). Michael Ritter argued that, "…the autistic child has a deficiency of fantasy rather than an excess," (Kirkham, 2017, p 113). This led to childhood schizophrenia being removed from the DSM III and replaced with Infantile Autism Disorder (remember that one, supposedly "discovered" by Kanner?) (Kirkham 2017) (DSM-III, 1980). By the DSM V which came out in 2013, the name "Asperger's Syndrome" had been removed and all those with that diagnosis as well as "Infantile Autism Disorder" now fit into the larger umbrella diagnosis of "Autism Spectrum Disorder" or ASD, which is currently still the official name.

This era also saw a rise in organizations created for advocacy for children and families with autism. During this time, both the "Autism Society of America" (ASA) and "National Autistic Society" were established. While both of these were run by families of people with autism, more organizations would soon arise that were run by actual autistic people, such as the "American Self Advocacy Network" (ASAN). They argued that "[autism] …is a neutral difference rather than a deficit," (Kirkham, 2017, p 115). Additionally, organizations such as the "Autism Friends Network" began to speak about about the terrible things being done to autistic

children, and how they would be called torture if they were done to neurotypical children (Sandoval-Norton et al., 2021).

This leads us to today, where many autistic people are coming forward to say that Applied Behavioral Analysis specifically has been a detriment to their lives, left them with trauma and anxiety disorders, and taken away their identity and sense of self.

What's Wrong with ABA?

"Withholding rewards was a part of ABA. Making kids talk or sign, even when it is clearly not the best form of communication for them, was part of ABA. Extinguishing play skills were part of ABA. Forcing compliance was part of ABA. If I didn't want to do any of those things, it meant not being an ABA therapist," (anxiousadvocate, 2015).

When reading discourse on ABA and autism, you will likely come across people who say that there are "good" and "bad" kinds of ABA, or that it is not in itself inherently bad and the negative experiences people have had has more to do with those who were conducting the therapy than the therapy itself. However, Anxious Advocate, a former ABA therapist, argues against this in the quote included at the beginning of this chapter.

A Dark History

As we learned earlier, behavioral analysis is a term coined by Sidney Bijou that refers to the larger field of behavioral sciences, and contains many smaller branches of psychology inside itself. Before ABA, people such as Charles Forster worked with the famous father of behaviorism, B.F. Skinner, to investigate autism through observable behaviors (Kirkham, 2017). Because treatments for autism in the 1960s were administered at boarding schools or institutions, psychologists would often have to perform a "parentectomy" where the child was completely removed from contact with family members (Kirkham, 2017). This is also likely due to the myth of the "refrigerator mother" mentioned earlier: the idea was that mothers were so cold and

removed that they couldn't teach their child how to emote properly. There was also an idea of a "smother mother", which was one who spent *too* much time with her child and doted over them obsessively to the point of them developing social difficulties (Kirkham, 2017); (Bettelheim, 1967). Obviously, these ideas were later proven to be false, and likely stemmed from the rampant sexism common in that period of time.

Applied Behavior Analysis did not come into existence until 1961, when a man named Ivaar Lovaas became an assistant professor at UCLA (Kirkham, 2017). Unlike previous approaches, Lovaas did not require children to be sent to an institution, and also didn't blame parents for their child's behavior. Instead, he believed that children with autism simply needed a different response to their behavior, and directly involved parents in the process of changing it. Lovaas worked with autistic children for a while before developing ABA, a method that used both positive reinforcement and "aversives" (a negative taste, smell, sensation, or other stimulus) to target challenging behaviors in children with autism. Lovaas performed a number of studies in order to prove that his new method, ABA, was effective, and by 1968, the first issue of the Journal of Applied Behavioral Analysis was released (Kirkham, 2017).

One particular autistic child he worked with was named Beth. She had some self-injurious behavior which he wanted to fix, and so each time she began to perform the behavior, he would slap her hand or bottom, administer electric shocks to the wrist, or place her in isolation.

> Additionally, he noted that Beth struck her head against the sharpest available surface. He concluded that Beth was deliberately sabotaging his experiment and beat her until she stopped. Seeing that this stopped her self-injury, Lovaas began to use such 'aversives' regularly, initially through beatings and later through shocks and the withholding of food (Kirkham, 2017).

While some thought this was cruel, he pointed out that it was effective enough to stop the harmful behaviors, which allowed her to live at home rather than in an institution. Lovaas also used hand slapping and yelling to stop unwanted behaviors in other children (Lovaas, 1987).

Additionally, there is a lesser known piece of Lovaas's work which changed the lives of an already oppressed group of individuals for the worse. Around the same time he started his work on autism, Lovaas was also working on another study: The Feminine Boy Project. Using the same principles of behavioral analysis, Lovaas attempted to rid gender non-conforming children of the characteristics he and his colleagues believed to be inappropriate for that gender to exhibit. This led to the huge and terrible field of "conversion therapy" which sought to make LGBTQIA+ individuals "normal" by using ABA to "train" them to be heterosexual or present their gender in the way therapists deemed to be "correct". Today, many more people are aware that conversion therapy for LGBTQIA+ people is harmful and wrong, but far fewer people think its wrong to use that same type of therapy on autistic people (Gibson & Douglas, 2018). Some autistic people believe ABA to be a form of "Autistic Conversion Therapy", a term coined by autistic scholar Amy Sequenzia.

Unfortunately, Lovaas wasn't the only one using harmful aversives on children during this time. In 1984 Friman published his study, "Effects of Punishment Procedures on the Self Stimulatory Behavior of an Autistic Child". In this study, they tried using various punishments to figure out which was most effective at eliminating a self-stimulatory hand touching behavior one particular child often used. They argued that the behavior needed to be addressed because it could lead to "more bizarre forms of self stimulation" (Roscignio, 2017, p 409). The three punishments they tested were misting the child with water in the face, forcing him to drink

lemon juice, and force feeding him vinegar. They found that the water was the most effective because, “His reaction [to the other two punishments] consisted of trunk twisting, arm-flapping, and leg extension as well as grimacing, spitting, coughing, screaming, and crying.” (Roscignio, 2017, p 413). In any other situation, it is likely that these behaviors would be seen as a clear sign of distress in a child, but in this study they were simply seen as an inconvenience. This is likely due to the fact that many people back then functioned under the idea that being autistic “negates personhood” (Roscignio, 2017, p 416).

At another institute in Florida in the 1970s, a doctoral level professional physically, sexually, and emotionally abused a number of autistic children leaving them with lasting trauma. “Examples of his practices included forced masturbation for individuals caught masturbating, public shaming of individuals caught lying, contingent beatings with a wooden paddle for running away, excessive use of lengthy exclusion, among others,” (Johnston et al., 2017). Other forms of “behavior modification,” which is what these practices were referred to as at the time, included psychosurgery, psychotropic drugs, physical restraint, sensory deprivation, timeout boxes, and starving children.

Although many supported Lovaas’s work and that of other behavior analysts, there was a lot of apprehension around the use of physical aversives to curb unwanted behaviors. By the late 1970s, Lovaas stopped using physical aversives. And by 1988, the NSAC banned the use of them, though researchers such as Bernard Rimland and others continued their use, especially for self injurious behaviors that posed serious physical danger to children, such as hitting one’s head against hard surfaces (Kirkham, 2017).

Although this may have been the end for most physical aversives being used on autistic children, there are unfortunately some institutions that still utilize them to this day. One of the biggest culprits of this is the Judge Rotenberg Center, which uses shock therapy on students with autism. This is done using a gradual electronic decelerator (GED). “The GED device is carried by the student in a backpack and controlled by staff members, and delivers charges of up to 41 milliamps, which is 10 times the amperage used in most stun guns, to the students legs, arms, hands, feet, fingers, or torso via electrodes placed on their skin,” (Roscignio, 2017, p 414). Multiple students have come home with lasting injuries from these devices, including burns, and lawsuits have been filed against the institution, but it has yet to be shut down or to discontinue the use of GEDs.

Another common practice still used in ABA today is physical restraint. While it is supposed to be used only when they are seen as a physical threat to themselves or others, staff have been seen using it when they feel a student is just “too much to handle”. Restraint can sometimes look like two or more adults physically placing a child in a hold which keeps them from moving their arms and/or legs, or placing them in an isolated, padded room for a period of time until they have calmed down. Autistic people have asserted that the use of restraint causes anxiety and PTSD (Anonymous, 2021), yet most schools and institutions still utilize at least some form of restraint, simply because they haven’t found a better way of dealing with certain behaviors.

Finally, some types of aversives still used today are more subtle, such as purposefully playing music or sounds that students don’t like, or withholding certain comforts like a child’s favorite toy (Trew, 2021). In general, aversives are used much less frequently than they used to

be, but unfortunately they are not the only thing about ABA which can cause lasting harm to the autistic people receiving it.

ABA Encourages "Masking"

(21andsensory, 2022)

One of the biggest issues with ABA that #actuallyautistic[5] people have mentioned is the way that they were taught to "mask" their natural reactions. As mentioned earlier, masking or "camouflaging" is where autistic people hide their natural autistic traits, such as stimming, unique facial expressions or cadence in speech, and impulses such as talking about their special interest, in order to appear more neurotypical (Beardon, 2017). The graphic included above was created by an autistic person and outlines some of the ways in which masking can manifest itself

[5] #actuallyautistic is a hashtag used on various virtual platforms including Tik-Tok, Twitter, Facebook, Instagram, and blogs to signify that the person speaking is someone who has autism. It has been helpful in distinguishing the voices of actual neurodivergent folks from those who may try to speak over or for them.

in everyday life. It's a learned behavior, and is exhausting, as it requires a lot of effort to pretend to be someone you're not, especially when you might not even fully understand the motivation behind all of the behaviors you are performing. It can also lead to "mystification", which is a confusion between inner and outer realities and can lead people to deny or ignore their own emotions (Anonymous, 2021). In other words, masking often requires invalidating one's own emotions or reactions to a situation in order to fit in or be perceived as "normal". Masking can look like suppressing a need to stim, laughing at a joke you don't understand, changing the way you speak, or even developing an entire personality to use in public that completely differs from who you are when you are alone.

Masking can also give the impression of more ability or comfort in an area than a person might actually have, which results in a lack of support and intense feelings of stress from trying to understand how you are "supposed to" behave. This build up of stress can often lead to a meltdown (Beardon, 2017). These meltdowns can be caused by the very behaviors people are being asked to perform. Something that might feel fine to do for a neurotypical person, such as making eye contact with someone, can be a huge and exhausting challenge for an autistic person (Ryan, 2010). Someone might be very good at pretending to be neurotypical, and it may become second nature to them. But nothing can change the way they perceive the world around them and how that affects their emotions, and stripping them of their coping skills and natural responses can lead them to feel an increased level of stress and confusion.

For example, perhaps an autistic child dislikes birthday parties due to the loud noises and large number of people. They may be told (by an ABA therapist or a family member) that they *should* like birthday parties, and that not liking them makes them a "party pooper". So, they try

to ignore those feelings and pretend like they are having a good time. That doesn't mean the feelings ever went away, they just hide them so that others don't get upset at them for not liking the party. This makes it more likely that the child might have a meltdown when they get home, and if their parents aren't educated on the subject, they might even be punished for that natural reaction to a stressful situation.

Another common situation for children with autism is the stress of going to the grocery store, "If an autistic child who screams every time he is taken to the supermarket is trained not to…he may still be experiencing pain from the fluorescent lights and crush of strangers," (Kirkham, 2017, p 116). Unfortunately, these repercussions of masking are very common among those who received ABA therapy at some point in their life. Children who are able to use stimming as a self regulatory behavior and not receive negative feedback for it, or who are taught to communicate about their sensory problems instead of ignoring them, often do much better at handling stressful situations than those who received intensive ABA (Autmazing, 2021).

Compliance

You may be wondering, how exactly does ABA teach harmful habits like masking if it is aimed at only extinguishing "harmful" behaviors? Well, it happens through the practice of compliance training,

> The rule is, once you give a command as an ABA therapist, you must follow through with it no matter what. If a child tries to cry or escape or engage in any other 'behaviors', you can't give in, because then you are only reinforcing their bad behaviors and making it more likely that they'll use them in the future. (anxiousadvocate, 2015)

This same idea of compliance is what was referred to earlier as "errorless teaching". It keeps the child from being directly told that they are making a mistake, because they are stuck in the lesson until they do it correctly. However, it does not provide the child with any way to say

no. ABA teaches that you are either complying or you aren't, and how you feel should be ignored (Anonymous, 2021).

Not only does this take away autistic children's communication skills, it is often aimed at getting rid of behaviors which can be self soothing to them (Kirkham, 2017). If a child with autism is feeling overstimulated, they might attempt to self regulate using by stimming. However, ABA is often used to teach children to suppress or hide these behaviors completely.

One autistic individual made this analogy in response to why the idea that some kinds of ABA repressing stims is wrong, "One example I like to use is: would you hold down the hand of someone communicating in sign language? No? Then why would you hold down the hand of an autistic child? It enables us to regulate ourselves, destress, and communicate how we are feeling also," (Stop ABA Support Autistics, 2019). For those who struggle with spoken language, behavior can be a crucial form of communication with those around them. Sadly, this is only one way which ABA can send autistic people in the wrong direction.

Post-Traumatic Stress Disorder

ABA has been empirically shown to lead to PTSD in autistic children (Leaf et al., 2021). One study looked at a group of children and adults who either had or had not received ABA (random assignment is rarely possible in these situations due to ethical concerns). Among the participants, 46% of children who received ABA therapy met the diagnostic threshold for PTSD. Adults who were exposed to ABA had a 41% higher rate of PTSD symptoms than those who had not been, and children had a 130% higher rate (Kupferstein, 2018). Respondents of all ages who were exposed to ABA were 86% more likely to meet PTSD criteria than those who were not (Kupferstein, 2018). These results are likely exacerbated by the fact that PTSD can be much

more severe in those with intellectual disabilities (which are comorbid with autism) (Mevisson et al., 2010). “With autism, the epigenetic effects of gene-gene interactions may act as a predisposition for PTSD based on hyperactivity to mild exposures,” (Kupferstein, 2018, p 20).

The study also found that autistic children started to show PTSD symptoms very soon after beginning ABA therapy, “…nearly half of ABA-exposed autistic children will be expected to meet the PTSD criteria 4 weeks after commencing the intervention; if ABA persists, there will tend to be an increase in parent satisfaction despite no decrease in PTSS severity,” (Kupferstein, 2018, p 19). Considering some children are enrolled in ABA programs from an early age all the way through high school, it is concerning to think that PTSD symptoms could be present throughout their entire childhood. Additionally, the idea that parents are increasingly happy with the therapy while their children are experiencing the same (if not higher) levels of stress sadly makes sense when we look at it from the perspective of ABA teaching compliance. Of course a parent would be overjoyed to see their child finally following directions, while at the same time the child would suffer from not being able to express that they are not happy to be doing so. ABA exposed participants also had increased aggression, self harm, shame, and low self esteem (Kupferstein, 2018).

Other findings from this study showed that the PTSD and trauma symptoms carry over to everyday life for kids. Children exposed to ABA reacted with fight, flight, or freeze in reaction to tasks that their non-exposed peers found enjoyable (Kupferstein, 2018). This is likely because special toys and games that the child enjoys are often used to manipulate their behavior in ABA therapy, so they learn to associate tasks with stress and work instead of fun.

One family's heartbreaking open letter articulates the results of ABA on their son, "The 'recovery' we were promised for our son turned out to be an experimental, operationally defined term in the behavioral language …What was 'extinguished' was not an isolated 'tantrum behavior' but in fact our son's basic sense of security and safety, his ability to regulate his emotional system, and his understanding of moral behavior (i.e. that 'when I'm hurting adults will help me)," (Anonymous, 2021). In the letter, the family describes how their vibrant, happy toddler immediately changed after a traumatic encounter where an RBT physically forced him into a chair and refused to let him stop the session despite his constant crying, screaming, and begging.

> The next 25 minutes were filled with a cacophony of sounds that were irreconcilably divergent and horrible. My son crying terribly - the consultant almost simultaneously clapping and saying "Good boy!" My son screaming - the consultant loudly demanding that he "kiss" and "hug." My son trying desperately to escape - their clapping. My son throwing the "reinforcers" - the consultant brutally yelling at him to pick them up. Their asking him to "touch his nose and head" - him falling out of the chair and screaming "go see mummy! go see daddy! pee on the toilet!! (Anonymous, 2021).

The tactics this family described, though not always implemented so aggressively, are commonly used in ABA. Often, if a child doesn't understand a direction or gives an incorrect answer, therapists will give them an instruction they know the child can comply with, like touching a body part or giving a hug. Clapping is used frequently as a way to practice mimicry with young children.

Although these strategies for changing behavior may seem harmless on the surface, this story illustrates how easily one bad session can scar a child for a long time after. These are just some of the many repercussions of "extinction": you are not just extinguishing a behavior but a form of communication, and often an expression of an emotion (Anonymous, 2021).

While there are many studies backing up ABA as "effective" in the case of compliance, "…most literature reviews and studies evaluating procedures involving extinction [of behaviors] did not include direct evaluations of possible trauma," (Leaf et al., 2021, p 7). In other words, Kupferstein's study is one of the first and few studies that actually look at the emotional effects of this therapy. Additionally, no larger studies have been conducted to look at the scale of the problem and analyze exactly what percentage of people who have been through ABA experience these negative outcomes.

However, there are plenty of personal stories available online about these experiences. Another account from a (self-proclaimed) survivor of ABA:

> They used food deprivation in my program and they made us pair up and do it to each other. I feel incredible guilt over this. Every morning I'd cut up a peanut butter and jelly sandwich into as many pieces as possible. Each piece was a little bigger than an m&m. Then I'd be told to force this non-verbal autistic boy to do behaviors for each piece of the sandwich. He'd cry, hit his head in frustration, and say 'hungry' which was one of like four words he could use (Fahrenheit, 2020).

It is likely that the boy's parents were thrilled with the fact that he was finally speaking, but they might be totally unaware of how it was done, or simply have accepted the fact that food is the only motivating factor for their child to do what they want. While food deprivation is a less common practice in ABA today, the reality is that a large number of children still work for food, including anything from candy to a piece of their lunch. The effects of this association between food and reward that these children form are grossly under-researched, though a number of autistic adults have expressed that the therapy led to disordered eating patterns in their own lives (Fahrenheit, 2020).

Another issue that autistic advocates have pointed out is the fact that the command-compliance pattern of ABA, which requires autistic children to perform specific

behaviors immediately after being asked, can sometimes directly conflict with conditions the children have or characteristics of autism. Motor apraxia, for example, is a condition where an individual is physically unable to perform certain actions at certain times, and has been found to be comorbid with autism (Matson, 2011). Therefore, when an ABA therapist withholds a favorite toy from a child until they "touch their nose", it is possible that the child is physically unable to perform that task at that moment. This could lead to the child feeling a sense of failure over something that they can't control.

You may be wondering why, with all of these issues, there are still so many studies backing up ABA as an effective therapy. A big factor in this is the way the studies are being designed in the first place.

Flaws in Research Design

The most famous study cited by ABA enthusiasts is Lovass's from 1987, which found that half the participants experienced a "full recovery" from autism after participating. While this may appear to be a perfect outcome on the surface, a closer look at the quickly proves otherwise. To start, there were only 38 participants to begin with, and they did not use random assignment, a technique used by researchers in psychology to ensure that both the control and experimental group are comparable (Lovaas, 1987). In order to divide up the two groups, they simply based it off of availability. This could lead to a certain type of child being assigned to a certain group. In fact, it was later found that many children who were in the control group were already in ABA before the study began (Kirkham, 2017). The issue with not using random assignment is that the researchers cannot conclude with certainty that the differences in the outcome of the

experimental and control group are due to the actual intervention (perhaps the study would have had a different outcome if the control group had not received ABA before).

Additionally, children's age at intake for the control group was, on average, 6 months older when they started treatment than their experimental group counterparts (Eikseth, 2001). This might not seem like a lot, but young children are developing rapidly both physically and mentally, and 6 months can mean the difference between not speaking at all and speaking full sentences.

When designing his studies and training the therapists who worked under him, Lovaas expressed that he was not a believer in protocols. He said that if an approach was not effective, they should simply change it (Silberman, 2015). While this may seem on the surface like a faster way to finding the answer, it is dangerous in a research setting where consistency is key to making sure that the treatment is actually effective. Changing the protocol mid-study completely destroys the validity of the research.

Critics of the study have also pointed out the fact that the number of therapists Lovaas had administering the treatment, as well as the lack of clear protocols, meant each child could be receiving a very different therapy. In response, Lovaas said, "…anyone who drives is likely familiar with the varied skill level in drivers, even though a driver's license is required to drive legally. The field of ABA, as it relates to practice, is no different. There are varied repertoires and skill levels across practicing behavior analysts that are likely to impact the quality of the intervention they provide," (Leaf et. al, 2021, p 5). While this may be true, it is disturbing to think that the behavior analysts vary as much as drivers do. Although he is correct that there is a wide range of drivers on the road, no one is happy about that. Accidents happen every day, and

parents are incredibly cautious when it comes to who they allow their child to ride with. Most parents wouldn't give their child to any random driver, so why should they be expected to hand them over to any behavior analyst?

Lovaas's studies are not the only ABA research that have come under scrutiny in recent years. For one, ABA proponents have argued that withholding treatment from autistic children would be unethical, and even compared it to withholding chemotherapy from a cancer patient (Houten, et al., 1988). This has made it very difficult to perform studies where the control group is receiving no treatment, or even an alternative, because it is considered to be cruel to withhold it from the child.

Another disturbing aspect of current autism treatment research is the high rate of people conducting studies who have conflict of interests (COIs). When conducting research in the field of psychology, it is vital that researchers have as few preconceived biases about the outcome of the experiment as possible, as it could skew the results. It is very easy to get caught up in the idea that you *want* something to be true, and then accidentally design a study that backs that up, even if it is not the case. Because of this, researchers are expected to be transparent about their COIs, and avoid working on studies which could be affected by said COIs when possible. However, one recent study looked at the number of COIs in the studies published over the course of a year on ABA autism treatment, and found that 84% of studies had at least one author with a COI (meaning they worked in the field of ABA and therefore had a bias towards the experiment coming out in favor of the therapy) but only reported these COIs 2% of the time (Beutel & Crowley, 2021). This is an alarming number, and is not being talked about nearly enough, especially in this field where so many people are depending on unbiased, accurate data.

Another troubling aspect of current ABA research is the lack of attention being paid to how the subjects are actually *feeling* throughout the therapy. While researchers and therapists do measure behaviors that may be the result of emotions, such as rates of "eloping" (trying to run away or escape from a family member or therapist), aggression, or self harming behaviors, there is not enough of an analysis of why these behaviors are occurring (and whether they could be related to the therapy itself) and there is no measure of self reported emotions by the subject. For example, it might be useful to *ask* the participants (via the mode of communication most comfortable to them) about their levels of anxiety, depression, or even just whether they are feeling "happy" or "sad" throughout the therapy if they are very young. This is especially important considering the high rates of comorbidity between autism and anxiety disorder (Zaboski & Storch, 2018).

One challenge that may arise when it comes to self report is when communication through AAC, sign language, or speech is not possible. If this is the case, it should be the top priority to provide a means for the child to express their wants and needs, and extreme care should be taken to ensure that the child is not under distress. This could even extend to having a parent or someone close to them present as often as possible who is familiar with their body language and understands how to tell when they are feeling overwhelmed. Additionally, behaviors should be taken as a means of expression instead of a means of "acting out". If the child is crying, eloping, or hurting themselves, the therapist should *first* consider the underlying cause of this: is the room too bright? Is the task too challenging? Is the child overstimulated, hungry, or scared? The therapist should consider, as often as possible, whether it is something *they* are doing that is causing the behavior, instead of placing the child at fault.

If the participant does have means of communication, consent should be acquired as often as possible, and choices should be given on what is being targeted, how, and when. There should be discussions between the therapist and child about emotions and how to express them. Regardless of communication abilities, there should be records of children's refusal to do certain tasks, and investigations on why the child might be avoiding them. This practice of looking at the underlying motivation is supposedly an important part of ABA, but too often the program overrides the child's wishes and wellbeing. This is to say that of course it is understandable that in some situations, a child may wish for something that is unsafe or simply impossible at the time, like running into traffic or only eating cookies all day and never doing work. However, it is important to take into account what is developmentally appropriate for a child, and to ensure that they do have as much control as possible for their age as long as it is safe and they are still learning and growing.

Other Concerns

Yet another problem which has been reported by those who have been through ABA is prompt dependency. As mentioned earlier, often in ABA, behaviors are taught through prompting. For example, if a behavioral technician wanted to teach a child to zip their backpack, they might start by prompting the child by saying "zip the backpack", or if the child needs more assistance at first, showing them how it is done by putting their hands over the child's and zipping. Eventually, the child might be able to do it with minimal assistance or prompting, but that is only in the context of the school. When the child is at home, or grows up and has all sorts of tasks that they are expected to complete, they might not be able to perform without some kind of prompt. This problem is exacerbated by the fact that those with autism have, on average, a

more difficult time with tasks that require the use of certain aspects of executive function, particularly planning and mental flexibility (Hill, 2003). In other words, thinking about the larger plan for the day or changing routines according to what is the top priority can be especially challenging for some autistic people. This issue is especially present for those with low support needs who are able to live independently, and must manage organizing and executing day to day tasks (Fahrenheit, 2020). The structure of ABA, which focuses on training people to exhibit certain behaviors when told to do so, is only useful for a population which is being told what to do, and leaves them without tools to perform those tasks on their own. Additionally, those who are able to live with some level of independence are left with no support at all.

Finally, a major concern which is very underresearched is the concept that teaching children to be obedient and always comply even if they feel distress, discomfort, or pain can also lead to an increased vulnerability to physical or sexual abuse. This is especially true for children with developmental disabilities, a group which has been found to be twice as likely to experience sexual abuse (Mansell, Sobsey, and Moskal, 1998). One autistic individual and sexual abuse survivor bravely shared their story on an autism advocacy website, illustrating the way ABA primed her for abuse, “When I was 9 years old, I willingly performed oral sex for a teenage boy who was much older than me. He did exactly what my ABA therapist did: he told me that he wanted me to do something I wasn’t comfortable doing, and he offered me my special interest, a pokémon toy, for my ‘compliance’,” (Fahrenheit, 2020).

Some might argue that the problem of increased abuse in this group of individuals is something that could be fixed simply by advising ABA therapists to pay more attention to the emotions of the people they are working with and including more discussion on topics of

consent. However, this practice of ignoring the feelings of the client is deeply entwined with ABA itself, "Unlike psychoanalysis, behavioral views of human learning and sociality are not interested in causes or the psychic interiority of human behavior and cognition," (Gibson & Douglas, 2018, p 9). In other words, it is inherent to the practice of ABA to ignore the underlying *emotional* meaning behind the behaviors, even if they are looking for an antecedent. Additionally, because many children start ABA with little to no means of communication, it is difficult to gain consent from some individuals in the first place, let alone lead a discussion about it, until much later in the therapy. By then, the idea of being violated or forced to do things against their will has already been demonstrated numerous times.

There are countless more examples of how ABA has harmed autistic people, and many of their stories are posted online on various advocacy websites and social media pages. The following excerpts were pulled from an anonymous Google forms survey conducted through one of these advocacy websites, "Stop ABA Support Autistics", created by an autistic advocate to give a platform to those who have had negative experiences and raise awareness on the issue.

> From the mother of an autistic child: *My son was enrolled in the pre-k program. The teacher, also a BCBA, used ABA on him. We saw a huge shift in his overall well being and attitude. He now shows symptoms of anxiety and a need for rewards for any type of demand.*
>
> From an autistic couple: *My partner and I are both autistic, and by all accounts were very similar as children. My partner was diagnosed and sent to ABA, whereas I was not. Not only does my partner have more trouble regulating emotions and dealing with the emotions of others, but her mother, who was the one who'd enrolled her, is much more hostile toward harmless autistic behaviors such as stimming than my family is.*
>
> From a former ABA worker: *I saw signs of trauma in particular in children who had been in ABA for a long time, such as starting to pull out hair, a desire to please out of fear (e.g. repeating 'I'm happy, I'm happy' and trying to smile even when crying), and meltdowns triggered by the demands of ABA itself.*

> From an autistic individual who was abused in ABA: *I was physically restrained for not following instructions (quiet hand and eye contact bullshit). My hobbies were shamed and ridiculed and I was told to have more 'girly age appropriate hobbies.' I was forced to 'try' new foods (they were forced into my mouth and I was yelled at for vomiting afterwards.*

Despite all of this, ABA is still beloved by millions of people around the world.

Why Has ABA Persisted Despite its Faults?

"At varying rates of effectiveness and in constant dollars, this model estimates that cost savings range from $187,000 to $203,000 per [autistic] *child for ages 3-22 years, and from $656,000 to $1,082,000 per child for ages 3-55 years." (Jacobson et. al, 1998)*

ABA Supporters

For one, ABA therapy does have a huge number of supporters. While this is made up mostly of the family members of people with autism, there are some actual autistic people who believe that ABA can be a positive experience. While most people would agree that the methods Lovaas and others used in the past were wrong, some believe that ABA has taken a turn for the better in recent years. In a lot of modern ABA therapies, there is an understanding that stimming serves a function, and the goal is no longer to change the child so that they appear "less autistic". Instead, they focus on more functional behaviors like communication skills, avoiding dangerous or self harming behaviors, and learning skills to gain independence like brushing teeth or tying shoes. The new, better ABA doesn't use punishment, only rewards. It is play based, child led, and driven by communication. Sure, edible reinforcers are still used quite often, but as one autistic mother put it, "If it takes giving him a cookie to make him stop these dangerous behaviors and learn self-care, as well as communication, then I'm okay with it," (Lamb, 2019).

Some autistic people who have been through the therapy even state that it has helped them directly with their emotions. “I think the biggest and greatest thing I learned in ABA was how to control my anger. Before then, I would get very aggressive and kick and hurt others. With the therapy, I learned how to manage my anger and anxiety,” (Lowry, 2017). The new ABA often incorporates field trips, games, and choices on what to work on and when. It provides space for clients and their families to express their feelings about what behaviors are being targeted and the strategies being used to modify them.

However, it is important to consider that even if this new ABA is better, it doesn’t make up for the serious mistakes which have been made in the past, and are still being made today. There are still ABA therapies which do use harmful aversives. The lack of regulation of the therapy means that different children can be receiving wildly different treatments under the same name, a name which carries a lot of trauma for people. Even if the new ABA is improved, there needs to be more awareness and acknowledgement of the ways it has seriously harmed people in the past, and a more precise plan for ensuring that the abuse does not continue. Unfortunately, it is difficult to believe that serious reform will occur when ABA is currently such a booming and profit driven industry.

Money

Often in the United States, the first thing we consider when looking into treatment options for a medical concern is whether it is covered by insurance. Between the years 2010 and 2014, 38 states introduced laws requiring insurance companies to cover ABA (Kirkham, 2017). For many families, this was seen as a huge success: finally their insurance would cover the only therapy available for their autistic loved ones! However, it is important to think about how this

may have affected other treatments, as well as ABA itself. Perhaps part of the reason ABA is so popular now is *because* the healthcare model in the US only allows for this one type of therapy to be affordable to families (Kirkham, 2017). Not to mention that, "Major organizations (particularly Autism Speaks) have lobbied hard for Medicaid and insurance companies to cover ABA therapy for autistic children," (Sparrow, 2016). Now, if you are performing an alternative therapy for autism and want it to be covered by insurance, you often have to call it ABA in order to get insurance coverage, even if that's not what it is (Davison, 2018; anxiousadvocate, 2015). And even then, some states require the therapy be administered by a Registered Behavior Technician or Board Certified Behavior Analyst, which means families have no other options when it comes to the therapy they choose for their child (NCSL, 2022). Another reason why ABA might be pushed so heavily by doctors and lawmakers in the United States is because of how much cheaper it is for the country as a whole than other available options. ABA saves $187,000 to $203,000 per child in comparison to no treatment at all, when taking into account what it would cost to provide accommodations, housing, and other services for the rest of their lives (Jacobson et al., 1998).

And how did ABA come to be required by law to be covered by insurance in so many states in the first place? Because of hundreds of lawsuits where families argued that their child was not receiving an adequate level of care either in school or in a medical setting, and insurance companies, hospitals, and public schools were required by the court to pay for ABA (which is the therapy with the most evidence for being effective at this time) for the family to make up for it (Whitted Takiff, 2022). In other words, the laws stemmed from autistic children being neglected, abused, and receiving unequal educational opportunities. The families themselves were also

often roped into these lawsuits by ABA companies, says Ari Ne'eman, who is the president of the Autistic Self Advocacy Network and a leader of the neurodiversity movement, "'ABA has a predatory approach to parents,' … The message is that, if you don't work with an ABA provider, your child has no hope,'" (Raeburn, 2016).

Unfortunately, the laws which families are convinced are intended to provide increased support for these children have backfired for some, who find themselves being abused yet again whilst receiving what is supposed to be a therapeutic behavioral intervention. The Judge Rotenberg Center (JRC), a school specifically for autistic children with high support needs, recently won in a battle against the Food and Drug Administration (FDA) which sought to ban their use of electric shock therapy (EST). The FDA argued the use of EST's risks outweigh the benefits when it comes to the treatment of autistic youth, pointing out that it has been shown to have a number of harmful side effects including anxiety, depression, PTSD, burns and tissue damage. Additionally, they pointed out that this population in particular was at greater risk due to the fact that there are higher rates of communication difficulties. The JRC replied that shocking the children was a "last resort" and was required in order to keep the children safe, due to the fact that a number of their students had histories of aggressive behavior towards themselves and others (Setty, 2021). This is a rather weak argument though, considering that the JRC is one of the only remaining institutions to still use EST on children with autism. In the end the court ruled that the FDA did not have authority to change when healthcare providers use certain tactics (considering that EST can be used to treat disorders such as depression in an ethical way). This result was devastating to a large number of autistic advocates who have been trying to shut down the JRC altogether for many years.

It is much easier to force children to hide their sensory problems than actually address them and accommodate them. For example, if a child has a sensitivity to loud sounds and tends to yell when it gets too loud, it would be much more beneficial to give them noise canceling headphones than to teach them not to yell. However, many parents and teachers are opposed to ideas along these lines, due to the fact that wearing headphones in certain contexts could make a child stand out, which some argue could lead to bullying or isolation.

It is easier to teach them to fit in at a young age than to allow them to be different. When comparing the needs of a disabled child to a nondisabled child, yes the disabled child will cost more (Jacobson et al., 1998). But should that really be where our priorities are when it comes to disability? What is more important: a person's quality of life, or how much it will cost for them to exist comfortably?

Another unexpected way that state insurance mandates have affected the quality of ABA care is by increasing the profitability of the industry. While families may be saving money now that it is covered by insurance companies, those same companies are now paying private ABA companies for each of those sessions with each of those children, meaning it is becoming a more and more lucrative industry. On average, insurance companies are reimbursing ABA companies 95 dollars an hour for a session with a Board Certified Behavior Analyst (BCBA) and 65 dollars an hour for a session with a Registered Behavior Technician or RBT (note that RBTs are, on average, payed less than 20 dollars an hour) (ABAedu, 2019). As we have seen with other systems in our country, an increase in the potential profit for something can also mean a decrease in the quality of that commodity. Our culture in the United States thrives off of mass produced items being made as quickly as possible. The first McDonald's hamburger was probably made

with great care using local ingredients, but once the demand for it got larger, the quality of the product decreased. While many would still argue that a hamburger from McDonald's tastes good and is fast and easy to get, we all know that it is not made with genuine ingredients, and there are many horror stories of quality control gone wrong where people have found all kinds of terrible things in their food.

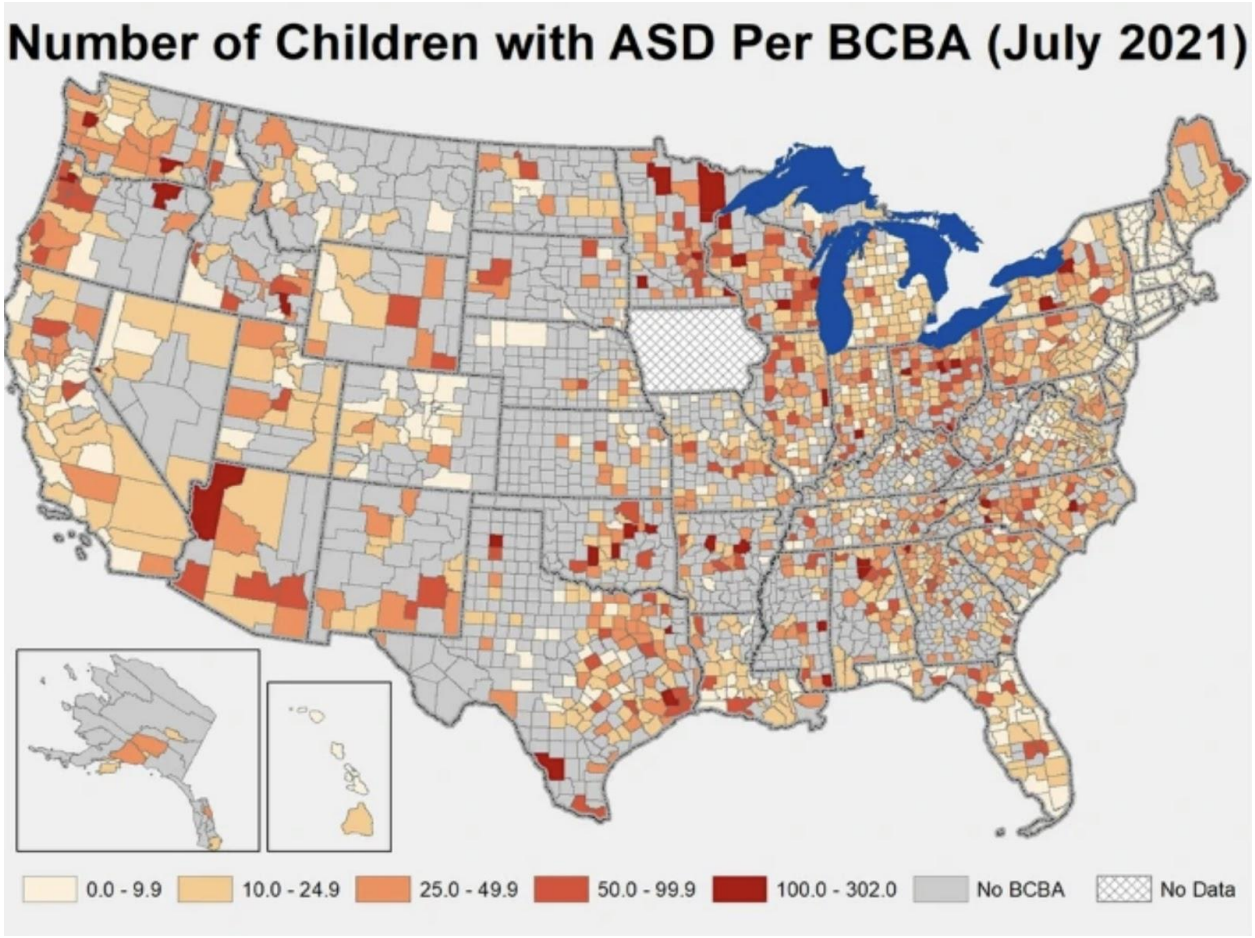
Yes, autism care has become a *commodity*, just like a hamburger, that can be bought and sold, and that means that many of the people doing this buying and selling likely do not have the client's best interest at heart. Researchers and families alike have voiced growing concern about the quality of the education and care being provided for people on the spectrum, and when you consider the ways the quality of the training being given to those who are administering the care has decreased over the past few years, you will understand why.

Certifications

ABA has provided a huge number of jobs and opportunities for financial gain to people of varying levels of expertise. "Lovaas' approach initiated a booming autism recovery industry…asserting the need for urgent, very intensive (expensive), professionally guided largely standardized approaches as the best/only hope for these children and their future selves," (Gibson & Douglas, 2018, p 20).

In 1998, certifications for who could administer ABA were created in order to better regulate the field (See Figure). The first two certified positions were BCBA (Board Certified Behavioral Analyst) and BCaBA (Board Certified Assistant Behavior Analyst). A BCBA is someone who can oversee BCaBAs and Registered Behavioral Technicians or RBTs, and they are in charge of creating a treatment plan and deciding what behaviors will be targeted for each

child. In order to become one, they have to complete a masters in ABA, psychology, education, or a related field and complete at least 1,500 hours of supervised ABA experience (Pepperdine, 2020). They are licensed to practice independently and can provide direct care, however, there are not nearly enough BCBAs in comparison to the number of children with autism in need of care in the US, so it is usually the case that they are acting as more of a supervisor. Below is a map created by researchers after conducting a study on the ratio of BCBAs to children with autism in the United States.



(Yingling et. al, 2022)

Keep in mind, it is recommended that even if a BCBA is overseeing a case and not directly implementing treatment (and has the help of a BCaBA), it is recommended that they take on no more than 10-15 clients at a time, depending on the needs of each individual client (Mandel, 2016).

The other certification available that holds the same responsibilities as a BCBA requires an even higher level of education and therefore there are even less of them. The Board Certified Behavioral Analyst-Doctoral (BCBA-D) must have either 1) a doctoral degree from an Associate for Behavior Analysis International accredited program, 2) hold an active BCBA certification and a doctoral degree, or 3) if their doctoral degree is from a non-accredited program, they must conduct a behavior analytic dissertation and either complete relevant doctoral coursework, complete a mentorship with a BCBA professional, or be an author of at least 2 peer-reviewed journal articles in the realm of behavior analysis (Pepperdine, 2020).

Working beneath the BCBAs and BCBA-Ds is the Board Certified Assistant Behavioral Analyst (BCaBA). They oversee RBTs and help with the BCBA's caseload. They need only a Bachelors in a related field with 180 hours of relevant coursework with a grade of C or higher, and 1,000 hours of supervised ABA experience (Pepperdine, 2020). They are not allowed to practice without the supervision of a BCBA.

Finally, below all of the above mentioned positions is the Registered Behavior Technician or RBT: requirements to become a RBT are simply that you have to be 18, have a high school diploma, pass background check, complete a 40 hour training, and then take and pass an RBT exam which consists of 85 multiple choice questions (10 of which are not even scored) (BACB, 2022). All of this can be done over the course of only a couple of weeks (and sometimes days,

according to a number of RBTs), and then you are allowed into schools and people's homes to begin administering "therapy" (Sohn, 2020). While most clinical psychologists are required to attend many years of schooling, including undergraduate and graduate school, in order to work directly with a patient, behavior technicians are not required to have *any* training on autism.

RBTs have reported feeling underprepared for the job, especially since the training is not specifically designed for working with autistic youth, despite the fact that that is the main use for ABA in the United States. For example, Terra Vance, a former teacher looking to get into the world of psychology, described her training experience as an RBT as incredibly unhelpful and short, in fact, she was able to complete it over the course of just one weekend. Then she was almost immediately thrown in with children with little supervision or instruction to guide her. "No one taught her how to change diapers or adequately manage aggression, she says, which she would have found more useful," (Sohn, 2020).

This underpreparedness that RBTs feel is likely due to two things. First, the ratio of BCBAs to RBTs: every BCBA is overseeing 10 to 20 RBTs at a time (which makes sense considering the map earlier which illustrated the number of children versus BCBAs and the fact that RBTs usually work one-on-one with their clients). Second, the training is simply not adequate enough. A week-long training might be sufficient for a job selling makeup, but when it comes to working with children in a therapeutic setting, it is disturbingly short.

Due to the high demand for RBTs and the large number of people completing the training with not enough BCBAs or BCaBAs to oversee them, training is often done totally online, and RBTs are left on their own to navigate the complexities of dealing with at home and in school care for children on the spectrum, many of which face communication barriers and have urgent

needs that have to be addressed (including being in physical danger due to self-harming behaviors). In order to combat the lack of regulation, a number of rigid rules are in place about what RBTs are supposed to say and do, and they are required to stick to them regardless of what kind of child they are working with or how the child reacts. While the consistency behind the technique may be useful in some instances, in others it can be a hindrance to the child's learning:

> Vance recognized that he [the autistic student] was communicating with humor and nuance by choosing lines to recite in various situations. But instead of engaging with him through movie lines, she was told by her supervisors to reward the boy with candy or cereal for following commands and completing trivial tasks, such as stacking blocks (Sohn, 2020).

RBTs are often faced with problems such as these: should I follow the rigid guidelines of this "golden standard" therapy, even when it feels like it is sending the child backward? How do I deal with situations I haven't been trained for, especially when my supervisor is already overwhelmed and rarely available (RBTs are required to be supervised by a BCBA or BCaBA only 30 minutes of every 10 hours they work, which is just *5% of the time*). Additionally, RBTs are the newest addition to the field, the certification was only created in 2014 as a response to the overwhelming demand for the therapy and the lack of professionals available to provide said care. From the start, many researchers and other professionals in the field raised concerns about how this change could affect the reliability of the therapy, arguing it may not be nearly as effective if it is not administered correctly (Leaf et. al, 2016). However, not enough studies have been conducted comparing RBT to BCBA administered care to see whether or not this is actually the case.

Another way RBT training may decrease the effectiveness of the therapy is due to the fact that they are taught very specific phrases to say over and over, regardless of how the child responds. "For example, technicians might be taught to use simple instructions, such as 'Do this,'

instead of varying language and altering words to match a child's ability to process complex instructions such as, 'Do what I'm doing,' or, 'Can you copy me?'" (Sohn, 2020). Using the exact same phrasing repeatedly decreases the generalizability of the skill being taught: if the child will only respond when asked in a very specific way, what are they to do in new situations where the other person may not be aware of the secret code required to unlock the behavior? It might be great to see a child respond to "Hello" with a greeting in return, but what if a classmate says "Hi" or "What's up?" instead?

These are just a few of the concerns raised surrounding the current system in place for administering ABA therapy. However, if you get to talking with RBTs, or even just poke around on the internet, you will find many more issues. One RBT was shocked when her training instructed her to buy a clicker at a pet store to use on her human, autistic clients (Sohn, 2020). Another mentioned that they were incredibly apprehensive when their supervisor instructed them not to tell clients or their families how long they had been working with the ABA company or how many hours of training they had received, even if they were explicitly asked (Anonymous, 2022).

So many ethical concerns have been raised surrounding ABA practices that a team of experts (made up of BCBAs and BCBA-Ds) created an "ABA Ethics Hotline" where families and professionals can seek guidance on what is and is not allowed in the Code of Ethics for Behavior Analysts. Jon Bailey, a BCBA-D, author, and one of the hotline operators, stated the following:

> I hear from parents that say, "This person doesn't know what they're doing." And then I hear from RBTs that say, "I wasn't trained to do this; I'm not getting any help. I've only worked with, say, children with language problems, and now they've given me a teenager who's aggressive." (Sohn, 2020)

Operators of the hotline and others argue that there simply aren't enough studies on RBT delivered ABA and its effectiveness. "…if you don't translate the research into practice, and if you don't monitor the practice, it's not the gold standard anymore," said Dr. Bailey (Sohn, 2020). Additionally, many professionals are advocating for a more flexible ABA, with increased training for RBTs and more hours of supervision, though this may not be possible with the current ratios mentioned before (Leaf et. al, 2016).

Lack of Regulation

In 2018, the Early Autism Project, which is the largest ABA provider in the United States, paid out over $8,000,000 to settle allegations of fraud. Some of these included billing Medicaid and other insurance companies for hours of therapy which were never actually performed and for work which is not meant to be covered by the insurance such as managerial duties in the company (U.S. Attorney's Office, 2018). This upsetting discovery is important in that it illustrates the fact that the ABA industry is one which is seeking to *profit* off of the families it is providing for and does so in ways that are not always ethical or safe.

This point is further supported by the fact that a number of lawsuits have been filed against ABA therapists for abuse, even as recently as this year, when an RBT assaulted a 16 year old, non-speaking girl in her own home during a therapy session (KTLA, 2022). Unfortunately, this is not the first time something like this has occurred. In 2013, another in-home ABA therapist was charged with physical and sexual abuse of a child, (Fox 6 Now Milwaukee, 2013). And in 2021, an entire ABA clinic was forced to shut down after 8 therapists were charged with emotional and physical abuse of the children in their care (Anderson, 2021). In 2018, Centria Healthcare, the largest autism therapy provider in Michigan, was charged with abuse after an

employee was caught on tape “taunting, dragging, pushing, and swatting a 5-year-old autistic girl during a therapy session,” on top of other allegations involving “…billing fraud, violating patient privacy, forgery, falsifying reports and employing unqualified people in an effort to boost profits,” (Wisely & Anderson, 2018). Despite this, Centria Healthcare still exists today in 14 different states and has worked with over 10,000 children.

Aside from all the issues, there is another, even more complex reason people dislike the therapy: it's geared towards the Western ideals of independence.

The American Ideals of Independence and Defining “Success”

In the United States, one of our biggest values is independence. We are an individualist society, one which prioritizes careers and nuclear families. Unlike other, more collectivist countries, we are expected to move out of our parents homes and live on our own as soon as we are able. From the time we are born, we are seen as a commodity, and our value is based upon what we can contribute to the labor market. The message is: if you aren’t able to work and provide for yourself, you aren’t valued. Because of this, those with disabilities have been historically seen as a burden, especially those who are unable to work, or who depend on others to care for them in order to survive. These ideas are so ingrained in our society that many still view disability as a tragedy, even with so many disabled people speaking out about how they don’t see it that way, and how they are proud of their disability and wouldn't want to change it even if they could.

The reality is: most of us will end up disabled in some way at some point in our lives, and even when we aren’t, we are still dependent on others, even if we don’t realize it. We depend on stairs to get us up and down. When we are young, we depend on our parents to care for us, and

when we are old, we depend on our children to do the same. Our society was built for a very specific type of person, someone who is "healthy" and hardworking and in their prime, a person which only exists for a brief period of time, if at all. Why are we so afraid of depending on others? Is that really what we want to be placing our values on as a society?

It's no surprise that the United States is the number one country in the world when it comes to the usage of ABA therapy (which decreases the cost of caring for autistic children by forcing them to be more compliant) and is *also* one of the richest countries without universal health care (Fisher, 2012). ABA makes people money through insurance. ABA makes people money by producing more workers. But that is not the priority in all places, and it is important to consider the way our culture contributes to our healthcare system, and our healthcare system to our morals and understanding of disability and dependence.

Many children who have been through ABA are seen as "success stories" but when you ask them and their families how they see it, they disagree. "The therapy was effective for Reid [an autistic individual]. In fact, it worked so well that he was mainstreamed into kindergarten without being told he had once had the diagnosis. He had been taught to be ashamed of his repetitive behaviors by his therapists, and later by his parents, who he assumes just followed the experts' advice. He never realized these were signs of his autism," (Raeburn, 2016). At first glance, you might see nothing wrong with this idea, that he is completely unaware of his autism and simply has to be occasionally reminded not to stim. But when you look at the accounts from autistic people that show the importance of stimming, and the importance of their autistic identity in their lives, it is difficult to look at this outcome as a success (Kapp et al, 2019).

The Social Model Of Autism

"It is clear that most people with autism are at a distinct disadvantage directly as a result of being autistic within a society that does not readily understand them," (Beardon, 2017, p 17).

It has been reported that reasons for heightened anxiety in people with autism include pressure, resistance to change, working to deadlines, responding to questions, making choices, and verbal communications (Beardon, 2017). These concerns could be addressed if autistic people weren't expected to meet the same rules and expectations by the neurotypical people around them. Many autistic people assert that they don't lack social skills among other autistic peers, they just don't understand the unwritten social rules neurotypical folks assert (Beardon, 2017).

Autism as Culture

In order to understand the ways autism can be viewed as a culture instead of a disorder, we must first look into the difference between the social and medical model of disability. In the medical model, it is believed that the root of disability is a physical, biological, or medical deficit. Under this model, disability is a pathology and the best way to handle it is to "cure" or treat it medically. The "solution" to disability, according to the medical model, is to eradicate it.

On the other side is the social model, which asserts that disability is actually caused by the way society *treats* disabled people. While there may be some aspects of some disabilities which require medical attention, the majority of what disabled people need is accommodations and respect from society. This model says that disability is a social construct, and that what might be considered a disability in one culture would not be in another. You may recall from

earlier in this paper that independence is something heavily valued in certain parts of the world, but that is not the case everywhere.

The social model would argue that the medical establishment has been pathologizing natural ways of being. Humans are diverse, and just because one person's body or mind might stray further from the "norm" more than another does, doesn't make them inherently impaired in any way. For example, only people who are bipedal can use stairs. But what if we all had wings? Then those who could walk would be viewed as disabled. Stairs would be seen as an "accommodation". Disability only exists because our society was designed for a specific type of person. And different societies and cultures might view certain people as having a disability, while others do not.

This is especially true for autism: since social norms vary across different cultures, it would make sense that there would be confusion between different groups about what the norm is in any given social situation. As we addressed earlier, ABA specifically targets social behaviors. The social model of disability asks: is this really necessary? What if we simply allowed autistic people to be, just the way they are, and didn't force them to conform to neurotypical social rules?

Here is where things get complicated when it comes to thinking of autism as a culture: autistic people are just as diverse as neurotypical people. Before the "diagnosis" for autism was invented, people with autism may have never even realized that there was a commonality between them. Some may argue then that the medical model is necessary to bring together groups through labeling them as "other". However, this is not getting to the root of the issue.

The reality is that all people have differences, and what many in autistic community are arguing for is a general respect for these differences and an understanding that not everyone thinks or perceives the world in the same way. Therefore, although the diagnosis of autism has helped a group of people with some similarities come together, it shouldn't have been necessary in the first place. What really needs to happen is not to divide everyone based on their differences, but to accept the fact that there are many different types of people in the world, and the most important thing is to treat one another with compassion and to work to understand those differences.

This is not to say, however, that "everyone's a little bit autistic". This is a myth that has been circulating recently, and it is a very dangerous one. Autism is a specific type of neurodivergence, and you are either autistic or you aren't. There are varying types of people with autism, and it can manifest itself in different ways. Each person with autism is different, just like each neurotypical person is. Additionally, neurotypical people will likely find that they have just as much in common with autistic people as they do with other neurotypical people. However, this does not mean that neurotypical people have autism.

Should Autism Be Treated as a Disorder?

Some reasons why categorizing people as autistic can be helpful are that it can enable others to understand their experience better, enable the autsitic individual to understand themself, aid in explaining certain reactions that individual may have, and reduce discrimination against that individual (Beardon, 2017). However, all of this is dependent on the situation. If someone generalizes autism too much or makes assumptions based on another autistic person they have met in the past, then the label is no longer helpful. It is only useful if we use it as a tool to better

understand the diverse motivation others might have for their behavior, and to understand that not everyone thinks about any given situation in the same way.

It may seem radical to assert that autism isn't a disorder. However, these types of changes in the way we think about things have happened time and time again throughout history. Not so long ago, left-handedness was thought of as a pathology, and children were punished and hit with rulers when they attempted to use that hand to write. Now, it is seen as a neutral difference, and left-handed people are given accommodations such as desks and scissors that fit their needs.

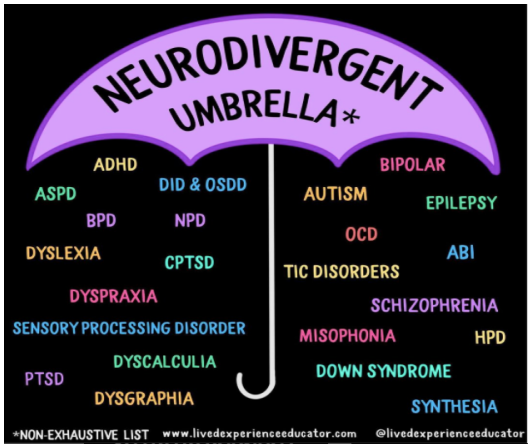
Similarly, LGBTQIA+ folks were seen as having a disorder in fairly recent years. However, many empirical studies as well as advocacy from LGBTQIA+ individuals eventually led people to realize that calling it a disorder was wrong, and it was removed from the DSM.

> This kind of myopia repeats throughout history. Seat belts were invented long before the automobile but weren't mandatory in cars until the 1960s. The first confirmed death from asbestos exposure was recorded in 1906, but the U.S. didn't start banning the substance until 1973. Every discovery in public health, no matter how significant, must compete with the traditions, assumptions and financial incentives of the society implementing it. (Hobbes, 2018).

It is important to consider, when deciding whether something is a disorder, what kind of challenges it presents to the individual experiencing it. Part of the issue with ABA is that many of the behaviors being eradicated are not necessarily harmful to the individual themselves, but they are seen as unnecessary, unattractive, or strange to those around them. It's also important to think about *who* is classifying behaviors as disordered and why. "The identification and meaning of the behaviors was…up to the clinician-researcher, and not for the parent, the rater, and certainly not the child to identify," (Gibson & Douglas, 2018, p 16). Most psychological disorders today are diagnosed on the basis of whether or not the individual themself is bothered by their own experience. If you are afraid of trains, but it isn't interfering with your daily life and

doesn't bother you, then it isn't a phobia. The only time this rule of diagnosing people based on their own experience does not apply is when they are a danger to themselves or others, which most autistic people are not.

Many members of the autistic community have expressed often that they are proud of their identity and wouldn't change it even if they did have a choice. A new term that has grown in popularity in recent years helps illustrate this different way of thinking about autism and other disabilities, "…neurodiversity: the notion that conditions like autism, dyslexia, and attention-deficit/hyperactivity disorder (ADHD) should be regarded as naturally occurring cognitive variations with distinctive strengths that have contributed to the evolution of technology and culture rather than mere deficits and dysfunctions," (Silberman, 2015, p 16). Neurodiversity is a term which can be used by anyone whose brain works in a different way than others, whether that is due to environmental or biological reasons. The important thing about the term neurodiverse is that it contains less negative connotations associated with it and isn't rooted in the weaknesses of those who fall into the category, unlike many medical terms historically used to refer to the people in said group. Here is an illustration of some of those who might identify themselves as "neurodivergent" done by autistic educator Sonny Jane:



(livedexperienceeducator, 2022)

It is important to emphasize here that there are *strengths* to all of these differences, ones that not only benefit the individual but our society as a whole as well. The autistic mind's affinity for lists may be seen at first as a deficit, but if we look at history, we see how necessary it is to have someone focused on listing everything in a particular category: think of the dictionary, the encyclopedia, or the millions of facts on the internet that people volunteered to write about for free. None of this would be possible without people who are interested and passionate about looking carefully at each individual detail.

Autistic people are often criticized for not understanding social norms. But in some ways, they are actually more efficient in their interactions. While a neurotypical person may hesitate to tell someone what they are really thinking for fear of hurting their feelings or coming off as rude, many autistic folks are incredibly direct and unafraid in their communication, giving way to more honest and open relationships.

Regardless of their strengths or weaknesses, autistic people deserve to be treated with respect and acceptance. They shouldn't have to have some special skill in order to be seen as a full human or to receive access. Autistic people shouldn't have to be seen as an "inspiration" or a "hero" for going about their daily lives with a disability. They are humans, just like the rest of us, and have the right to receive access to the world in a way that is comfortable for them.

What Does the Future Look Like?

"Don't take away your child's voice; take away their suffering. ABA is a cruel response to aggressive behavior. Meet that behavior with love, calm, support, and an investigative search for the source of your child's struggle instead. Learn why your child is getting so stressed out that they are frightening the people around them, and help make your child's life calmer, safer, and happier." (Sparrow, 2017)

One question I have asked myself time and time again while researching this topic is whether ABA is capable of redeeming itself. To be honest, I'm still not sure. I think that a lot of

good people are ABA therapists, and that they have good intentions. I know that there have been a lot of positive changes in ABA over the years, and many organizations no longer target autistic traits like stimming when they are administering the therapy, and instead focus on communication and daily life skills. However, the dark history of ABA and trauma so many have experienced will never go away. Because of this, some argue that it needs to be abolished completely.

New Ways of Thinking

The world is slowly starting to gain a better understanding of disability and the importance of including *all* people, regardless of their support needs. For example, the Individuals with Disabilities Education Act (IDEA) of 2004 sought to provide equal access to education for disabled people and has made a big impact on the opportunities available to disabled (and more specifically, autistic) children. This excerpt from the act illustrates the change in thinking that is starting to take place surrounding disability:

> Disability is a natural part of the human experience and in no way diminishes the rights of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency to individuals with disabilities. (IDEA, 2004)

Yet another example of the larger push for change is the United Nations Convention on the Rights of People with Disabilities, which altered and enriched the lives of disabled people by outlining their rights to accessibility, mobility, independent living, rehabilitation, autonomy, non-discrimination, inclusive education at all levels (including college and university), and acceptance of people with disabilities as a part of society. It also established that failure to provide adequate accommodations and support is a form of discrimination, opening up spaces

that disabled people were previously barred from. These guidelines have been adopted by a number of countries, and as a result millions of disabled people have seen a change in their quality of life. Additionally, more states are looking to consult disabled people on policies and practices which are related to them (United Nations, 2006).

Regardless of ABA's future, there needs to be more therapeutic options available for autistic people and their families. While speech therapy, occupational therapy, and physical therapy can help target certain skills, there has to be support for the problems that actual autistic people have expressed a need for. These include issues like anxiety, misunderstanding social situations, and increasing communications skills and self advocacy. More than anything, the narrative surrounding autism needs to shift from centering around what scientists and neurotypical people believe to actually hearing autistic voices.

Future Research

One urgent issue that needs to be addressed by researchers is the scale of the problem when it comes to ABA causing harm to autistic individuals. There have been no large scale studies looking at how autistic people are fairing emotionally post-ABA, which is a huge problem. The way that "success" is measured in research on the therapy is solely based on functioning and how others perceive the autistic individual, but there are no measures to gauge how that person is actually feeling throughout and after the therapy. In order to address this, researchers need to reach out to autistic adults who have been through ABA programs and hear what they have to say about the experience. It also means bringing in more autistic people to observe ABA and its development and giving them the authority to make the changes necessary to reduce (and hopefully one day eliminate) the negative impacts such as those highlighted in

this paper. Finally, research on autism and ABA needs to be expanded and diversified to include significantly more people of color, LGBTQIA+ people, people from lower income backgrounds, and needs to pull from a wider age range.

Accessibility

Diagnostic tools need to be re-evaluated to properly assess autism in *all* people, not just cisgender, white boys. Part of the path to this is the research mentioned above, but another piece is making autism screenings more accessible for anyone who is interested in having one. As of right now, professionals offering autism screening and diagnosis are hard to come by, with wait lists of over a year and many still not accepting insurance, meaning it can cost over 2000 dollars to get tested.

People are, thankfully, starting to understand the importance of accessibility in recent years. Airports, malls, grocery stores, and others have started to create sensory friendly rooms or hours for shopping. Hopefully these changes will continue to be made and all spaces will become more accessible to all disabled people.

What You Can Do

It is understandable that ABA therapists and those who have had positive experiences with the therapy may struggle to hear some of these critiques, especially considering the amount of time and money that they have likely invested. And of course, it is important to acknowledge that ABA has been successful in helping a number of people in many ways. But it is imperative that regardless of how strongly you believe in ABA, you are open to hearing the ways that it could be improved, especially when it is coming from the very people it was created for. Currently, the discourse surrounding the therapy online and in more academic settings is deeply

one sided, and those who speak out against it are largely silenced or ignored. This is not the way to a better future.

No matter who you are, you have the power to listen. Take the time to hear autistic voices, educate yourself on these issues, and show support for the organizations that are actually aimed at helping the cause. Over the years, Autism Speaks specifically has done a lot of harm to the community, and ensuring that you are not supporting it is one easy way you can help. You can sign petitions that stop unethical organizations like the Judge Rotenberg Center. Sign pledges not to use harmful language anymore. And most importantly, you can recognize your own mistakes and use them as an opportunity for growth and learning.

Resources

- **Sign the petition to shut down Judge Rotenberg Center:**

  https://www.change.org/p/massachusetts-state-house-close-down-judge-rotenberg-center-for-human-rights-violations

- **Take a pledge to stop using harmful and outdated language:**

  https://www.specialolympicsma.org/what-we-do/transformative-education/r-word/#:~:text=Spread%20the%20Word%20to%20End%20the%20Word%E2%84%A2%20is%20an,stop%20using%20the%20R%2Dword.

- **Donate to the Autism Self Advocacy Network (ASAN):**

  https://secure.everyaction.com/uEXr_TqeBkqmQMlvi7itXg2

- **Read more testimonies from autistic people on their experience with ABA**

  https://stopabasupportautistics.home.blog/2019/08/11/the-great-big-aba-opposition-resource-list/

Glossary

Applied Behavioral Analysis (ABA): A behavioral therapy designed to modify socially significant behaviors.

Autism Spectrum Disorder (ASD): A disorder defined in the DSM V by three main characteristics: challenges in social communication and interaction, repetitive and restrictive behaviors, and highly restricted and fixated interests.

Aversive: An unpleasant sensation performed on a subject to reduce the frequency of an unwanted behavior.

Board Certified Behavior Analyst (BCBA): A graduate-level certified professional who specializes in behavior modification through the use of ABA.

Board Certified Behavior Analyst-Doctoral (BCBA-D): A doctoral-level certified professional who specializes in behavior modification through the use of ABA.

Board Certified Assistant Behavior Analyst (BCaBA): An undergraduate-level certified professional who specializes in behavior modification through the use of ABA.

Breakdown: An experience of total physical, mental, and/or emotional exhaustion by an autistic individual caused by living in a world designed for neurotypical people. Also called "autistic burnout".

Diagnostic and Statistical Manual of Mental Disorders (DSM): A publication by the American Psychiatric Association which classifies mental disorders.

Discrete Trial Training (DTT): A form of ABA which uses reinforcers and direct instructions to shape behavior. Created by Ivaar Lovaas.

Early Intensive Behavioral Intervention (EIBI): A form of ABA which occurs as early as possible (usually around 3 to 4 years of age) and is intensive (20 to 40 hours per week).

Early Start Denver Model (ESDM): A form of ABA that utilizes developmental approaches to improve adaptive behavior in children between 12 and 48 months of age.

Electro-Convulsive Therapy (ECT): A procedure which sends small electric currents through the brain causing a short seizure.

Errorless Teaching: A form of teaching in which children do not experience the feeling of getting an answer "wrong", as they are prompted with the correct response immediately following the instruction.

Extinguish: To completely get rid of a behavior.

Fading: Decreasing the level of prompting used over time until the subject is able to perform the task independently.

Gradual Electronic Decelerator (GED): An aversive conditioning device which delivers a powerful electric shock to the skin immediately following unwanted behaviors.

Interspersal: A strategy in ABA where more challenging tasks are mixed in with easier ones to increase the confidence of the subject.

Mand: A request for something wanted or to end something unwanted.

Masking: A phenomenon in which an autistic individual attempts to appear to be neurotypical by hiding their natural autistic tendencies.

Medical Model: A way of looking at disabilities where they are seen as a deficit, or as something that should be fixed or eradicated.

Meltdown: An experience where an autistic individual loses control due to feeling overwhelmed which is often expressed verbally or physically.

Milieu Teaching: Arranging an environment to encourage specific behaviors and/or natural teaching opportunities.

Natural Environment Teaching (NET): A form of ABA which is performed in a space or situation which is familiar or preferable to the child, or is one which they would encounter in everyday life.

Natural Language Paradigm (NLP): The previous name for Pivotal Response Training or PRT.

Pairing: Using items, games, or other stimuli that the subject enjoys to associate positive feelings with the therapist providing ABA therapy.

Pivotal Response Training (PRT): A form of ABA which focuses on specific areas of the child's development such as motivation to learn and communication.

Prompt: A verbal or physical cue that leads the subject toward the desired behavior.

Registered Behavior Technician (RBT): A certified ABA paraprofessional who works under the supervision of a BCBA and provides direct care to the client.

Reinforcer: An object, food, or other stimulus which is enjoyable that is given to the subject in order to increase the frequency of a desired behavior.

Sequenced Instruction: Teaching a linear structure for activities or behaviors and breaking them up into manageable steps.

Shaping: The process of reinforcing behaviors that are close to the desired behavior until the desired behavior is reached.

Social Model: A way of looking at disability as a natural and neutral difference that does not need to be changed or fixed, but rather accepted and accommodated.

Stimming: A repetitive action or behavior which acts to regulate the emotions or sensory input of an individual.

Tact: A name for when a subject of ABA labels something in their environment.

Task Variation: Mixing up topics and forms of teaching in order to keep the subject interested.

Theory of Mind (TOM): One's ability to understand the mental states, desires, and beliefs of others.

Verbal Behavior Approach (VB): A form of ABA which emphasizes communication and is based off of a concept initially developed by B.F. Skinner.

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