“You Can’t Train Autism Out of Me”: Identifying Themes from Autistic Adults’ Social Media Content about Applied Behavior Analysis

by

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BA in Political Science, Pennsylvania State University, 2019

Submitted to the Graduate Faculty of the

School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Public Health

University of Pittsburgh

2022

UNIVERSITY OF PITTSBURGH

SCHOOL OF PUBLIC HEALTH

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June 15, 2022

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Autism spectrum disorder (ASD) is an increasingly common diagnosis, and identification of the best ways to support autistic children and their families is an important public health concern. Healthcare professionals commonly recommend Applied Behavior Analysis (ABA)-based interventions for children upon diagnosis, but autistic self-advocates often oppose ABA. To develop and refine childhood interventions that best meet the needs of autistic children, it is necessary to respect the input of autistic adults and to engage with them as autism experts. This thesis explores autistic adults’ perspectives on ABA using publicly available social media content.

A reflexive thematic analysis of 63 TikTok videos and four Facebook posts, made by a total of 51 unique creators, uncovered themes of harm caused by ABA, opposition to ABA as a field of practice, need for nuance in discussions of ABA, and conflict in discussions of ABA. Autistic creators expressed the belief that ABA harms autistic children and frustration that their opposition is often invalidated by professionals and caregivers. Several videos revealed conflict within the autistic community, and some creators called for nuanced discussions about ABA, noting that the priorities and needs of autistic people of color are not the same as those of white autistic people. The findings pinpoint aspects of ABA that are of concern to autistic adults and can help guide the development of future interventions. Moreover, the analysis highlights an ongoing need for inclusive, collaborative autism research that respects intersectionality and considers how autism affects people differently depending on their race and other identities. These findings have public health significance because of the rapid rise in ASD prevalence and the pressing need to critically examine childhood interventions.

Table of Contents

List of Tables

List of Figures

Preface

I want to thank and acknowledge all those whose support has been crucial to my success. To Dr. Terry, thank you for being a fantastic advisor who graciously offered advice and guidance starting from before I even entered this program. When a pandemic destroyed my carefully developed plans for time management and everything became infinitely more overwhelming, your support was indispensable. I greatly appreciate your good humor, patience, understanding, and warmth. Your guidance and feedback have contributed so much to this thesis and to my education. I am grateful as well to Dr. Sidani and Dr. Beck for being part of my committee. Thank you for sharing your time, offering valuable direction and suggestions that strengthened this thesis, and showing kindness throughout the process. I would also like to thank my other professors and peers in Public Health as well as GSPIA, from whom I have learned so much.

I want to acknowledge the TikTok and Facebook creators, too, without whose content this thesis would not be possible, whose candor and advocacy are so meaningful.

Finally, I want to express my enormous gratitude to my family and friends. You have all helped me reach my goals in both big and small ways.

To Doctor, Crouton, and Rosie, thanks for being such great cats. I appreciate your sweetness and nonstop chaotic energy; thanks for allowing me to boop your noses so frequently.

To my wife Amelia, thanks for your unyielding support through every round of “maybe I should just give up.” Your partnership is my biggest source of strength. Thanks for being both my rock and my soft place to land.

To my beautiful children, Caleb and Cordelia, thank you for being you. Your love and enthusiasm guide, comfort, and motivate me every day. I love you always.

1.0 Introduction

Autism has evolved over past century, from a rare condition that led only to institutionalization into a much more common condition with a range of outcomes. The most recent estimates suggest that more than two percent of children in the United States are diagnosed with autism spectrum disorder (ASD) (Maenner et al., 2021). Many of these children, upon diagnosis, will receive some type of intervention or service for their autism; many, in fact, will receive more than one. The most common interventions recommended to parents of newly diagnosed autistic children are those based on the science of Applied Behavior Analysis (ABA), which are conventional but increasingly contested (Devita-Raeburn, 2016). ABA-based interventions aim to increase desired behaviors and decrease unwanted behaviors, primarily by using rewards (Rudy, 2022). “ABA” most precisely refers to a group of related interventions that share a scientific basis, but the term is used throughout this thesis as though discussing a singular intervention. This mirrors the way that both opponents and supporters tend to discuss it in online spaces, and this use is common in the literature as well.

Autistic self-advocates often lead the opposition to ABA, and they frequently express their opinions in online spaces (Ask an Autistic, 2019). How to best help autistic children is a matter of public health concern, especially as more and more children are being diagnosed (World Health Organization [WHO], 2022). Regardless of the “effectiveness”[1] of ABA-based interventions, researchers and practitioners should be concerned about how the interventions are

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[1] Quotations are used here to emphasize that there is disagreement about what outcomes are even important or desired (Leadbitter et al., 2021; Ne’eman, 2021; Wiley-Mydske, 2021).

perceived by autistic people. Negative perceptions from the people who have experienced these interventions indicate that, effectiveness aside, they could be doing harm (Sandoval-Norton et al., 2021).

To further explore autistic adults' opinions about ABA and the factors underlying those opinions, this study analyzes social media videos collected from the TikTok platform and several Facebook posts from public pages. Autistic adults created this content, and it all relates to the topic of ABA. Specifically, this thesis sought to answer the following research question: What are the perspectives of autistic adults on the topic of ABA?

Given preexisting impressions of the ABA-related attitudes expressed by autistic adults online, it was expected from the outset that many of the perspectives uncovered would indicate strong opposition to ABA. However, the intentionally broad research question allowed for a flexible exploration of the range of opinions and for the inclusion of autistic adults who had experienced ABA as well as those who had not.

1.1 Notes on the Language Used

Thoughtful, carefully considered language is an essential aspect of inclusion and respect. Disability-related language has evolved over decades of activism, and it continues to evolve. At times, the recommendations of authoritative bodies conflict with the stated preferences of self-advocates. Recognizing that there is variation of preferences within the group, it is vital to assume that people are the final authorities on what language should be used to describe them. The language used in this thesis reflects thoughtful consideration based on a commitment to centering autistic people's language preferences.

Possibly the most common source of language-related conflict concerns the use of *identity-first* language (IFL) versus *people-first* language (PFL) (Dunn & Andrews, 2015) . Some disability advocates have argued in favor of PFL, but many disabled people have criticized it and promoted IFL (e.g., Liebowitz, 2015). Autistic adults seem to overwhelmingly prefer IFL ("autistic person") rather than PFL ("person with autism") (Bonnello, 2022; Bottema-Beutel, Kapp, et al., 2021; Brown, 2012; Kenny et al., 2016), so IFL is used here. Similarly, "autism" is used rather than "autism spectrum disorder" or "ASD," except when specifically referring to the diagnosis/diagnostic criteria.

Additionally, the term *allistic* is used to mean non-autistic. This reflects the language commonly used by autistic individuals in online spaces and beyond. The term gained popularity after its apparent first use in 2003 (Main), in a parody article that described the disorder of "allism" in order to mock the medicalization of autism. It was created as an antonym to autistic, using the prefix *allo*- (other) to contrast with *auto*- (self). The terms *neurodivergent* and *neurotypical* are also used in this paper. The paradigm of *neurodiversity* will be discussed in greater detail below. *Neurodivergent* refers to anyone whose brain functions differently from society's expectation, and *neurotypical* refers to those who seem to fall within the expected range (Villines, 2022). There is not necessarily clear agreement on what conditions make someone neurodivergent, but at the minimum, autism and other neurodevelopmental disorders are included. Someone who is neurodivergent may or may not be autistic. *Allistic* and *neurotypical* are used here for their precise meanings, not as synonyms.

Many autistic people dislike *functioning labels*, which make a distinction between "high-functioning" autism and "low-functioning" autism (Bottema-Beutel, Kapp, et al., 2021). Such labels can be imprecise and too often based on intelligence quotient (IQ) scores. For autistic children without intellectual disability, IQ scores are not a good indicator of adaptive functioning (Alvares et al., 2020), and many autistic people consider functioning labels a way to either deny support to those deemed “high-functioning” or deny agency to those deemed “low-functioning.” They also often note that an autistic person’s ability to “function” can vary across domains, so blanket functioning labels are unhelpful (Bottema-Beutel, Kapp, et al., 2021). This thesis will avoid the use of such terms and refer instead to specific characteristics or needs whenever possible.

Finally, *autism community* is a term sometimes used to include not only autistic people but also their parents, caregivers, relatives, and even the professionals who work with them. This paper deliberately refers to the *autistic community* instead, which includes only autistic individuals. When discussing a broader group inclusive of other stakeholders, the wording will make this clear.

1.2 Summary

The background chapter of this paper situates the current controversy around ABA within its historical context. This includes discussion of the evolution of autism and the emergence of the autism rights movement, as well as the historical development of ABA. This chapter additionally describes current ABA practice and common criticisms. Theoretical considerations are discussed, and the chapter ends with a consideration of autistic adults’ use of social media platforms and a brief overview of TikTok.

The next chapters describe the research methods used and the results of the present analysis. Discussion of the results considers what perspectives are represented and what knowledge can be gained from them. The discussion chapter also puts these perspectives into a broader context that considers systems of oppression and emphasizes the need for community inclusion in research. This paper’s final chapter addresses the public health significance of these findings and offers recommendations for future directions.

2.0 Background

For decades, autism's prevalence has been increasing rapidly in the United States (U.S.) and with it, interest in autism and autism research has increased as well (Doheny, 2008). In the 1960s and 1970s, the earliest autism prevalence studies in the U.S. and Europe reported rates that ranged from 2 to 4 per 10,000 (Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders et al., 2015; Lotter, 1966). Prevalence estimates began to increase in the 1980s and 1990s, and by the early 2000s, reported prevalence was between 60 to 70 per 10,000 (Fombonne, 2009; Van Naarden Braun et al., 2007). Most recently, 2018 estimates put the prevalence at 230 per 10,000 (Maenner et al., 2021).

These increases in prevalence cannot be separated from the evolution of autism as both a concept and a diagnosis. The idea of autism has changed and expanded dramatically over the past century, and approaches to addressing it have also shifted. As a result of research associating earlier intervention with better outcomes, efforts have supported universal screening beginning in early toddlerhood (Hyman et al., 2020). The goal of recognizing and diagnosing autism as early as possible is now well-established (Centers for Disease Control and Prevention [CDC], 2022b; Elder et al., 2017; National Institute of Child Health and Human Development [NICHD], 2021). In fact, some research has focused on developing methods to accurately diagnose autism in infants under the age of one (e.g., Nyström et al., 2019) so that intervention can begin even earlier. While no such methods are currently available, research efforts also seek to refine developmental screening tools to identify atypical development in infants between six and 18 months old, in order to begin intervention prior to an official diagnosis (Tanner & Dounavi, 2021).

The most common early autism interventions are behavioral interventions, though relationship-based approaches are available as well. In addition to or instead of these interventions, many children receive developmental interventions from speech-language pathologists, occupational therapists, and/or physical therapists (Centers for Disease Control and Prevention, 2022a).

Behavioral interventions use behavior modification techniques to decrease undesirable behaviors and increase desirable ones. ABA is a behavioral intervention often regarded as the most effective, the only evidence-based treatment, and the "gold standard" intervention (Autism Science Foundation, n.d.; Autism Speaks, n.d.-a; Campbell et al., 2020).

ABA is often strongly recommended upon a child's diagnosis (Hyman et al., 2020), and its proponents tend to strongly advocate for it (Walsh, 2011). However, many autistic adults have vocally opposed ABA (Kirkham, 2017). These criticisms have only recently become integrated into mainstream conversation about ABA, with several articles cataloguing the controversy (Child Mind Institute, n.d.; Devita-Raeburn, 2016). Still, in some cases this has been cursory and dismissive of anti-ABA arguments. Rarely has there been a genuine effort to center the perspectives of autistic people. In many cases, when autistic perspectives *are* centered in research, it is because the researchers are autistic (Jones, 2021). Even so, the past few years have seen a promising trend toward inclusive research (Nicolaidis et al., 2019).

Although autistic people have written at length about ABA in spaces all over the internet, little research has explored autistic people's perspectives on this topic. Developing a deeper understanding of autistic adults' ABA-related perspectives can inform early autism interventions by centering the voices of the people these interventions intend to help.

2.1 Autism

Many people are interested in or concerned about autism: researchers, parents, caregivers, educators, physicians, psychologists, and other healthcare workers. Autism is steeped in mythology, with various narratives falling in and out of fashion over the years. Attention to autism has grown as sharp increases in prevalence have led to its being discussed as an epidemic and identified as “an emerging public health problem” as early as 2003 (Newschaffer & Curran, 2003).

Autism has been described in various ways over the years. The most recent version of the *Diagnostic and Statistical Manual of Mental Disorders (*5th ed., text rev.; *DSM-5-TR*; American Psychiatric Association [APA], 2022) conceptualizes autism as a spectrum and defines autism spectrum disorder (ASD) as a neurodevelopmental disorder. To meet the diagnostic criteria for ASD, an individual must have “persistent impairment in reciprocal social communication and social interaction” and “restricted, repetitive patterns of behavior, interests, or activities” (APA, 2022). These symptoms must have been “present from early childhood” and “limit or impair everyday functioning” (APA, 2022). The *DSM-5-TR* notes that these symptoms can present in different ways depending on a variety of factors.

That many more children are now being diagnosed with autism is obvious. This story can be told in numbers. Early estimates, from prevalence studies conducted in the 1960s, put autism prevalence between one in 2000 and one in 5000 (Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders et al., 2015), but even by the 1990s, there was concern about seemingly increasing rates (Gillberg & Wing, 1999). One review of prevalence studies between 1966 and 1998 found that estimates increased with each year: the median estimate was one in 1923 across all studies but increased to one in 1389 for studies between 1989 and 1998 (Fombonne, 1999). In 2000, the CDC established the Autism and Developmental Disabilities Monitoring Network and began to collect surveillance data. That year, one in 150 U.S. children was identified as autistic (CDC, 2021). By 2012, this number had jumped to one in 68

(Christensen et al., 2016). It became one in 54 in 2014 (Maenner et al., 2020), and the most recent estimate, using 2018 data, is that one in 44 U.S. eight-year-olds is autistic (Maenner et al., 2021). To what extent these numbers represent an actual increase in prevalence is less clear.

The jump from one in 2000 to one in 44 is substantial, but debate persists over how much this can be attributed to expanded diagnostic criteria, increased identification of autism, and diagnostic substitution (Gerrard, 2022). This debate over the reality of an autism epidemic is not new (Lilienfeld & Arkowitz, 2012), but regardless of the reasons behind the increase in autism diagnoses, it means that more children than ever will be referred to autism intervention services.

2.1.1 History of Autism

Leo Kanner and Hans Asperger are now the names most associated with early descriptions of autism, but descriptions of autistic behaviors can be found much earlier in the psychiatric literature (Wing, 1997). In addition to these psychiatric accounts, many historical accounts of children and others with autistic-like traits also appeared prior to the use of the word *autism*, and some characters from myths or legends might also be seen as having autistic traits (Wing, 1997). When the term autism initially came into use for children, it was understood to be a childhood form of schizophrenia.[2] Swiss psychologist Eugen Bleuler first used the term "autism" in the early 20th century to refer to a withdrawal from reality in people with schizophrenia, a word that Bleuler had also coined (Evans, 2013). He described this symptom as

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[2] For instance, Bender (1947) described observations of "schizophrenic children," many of whom showed traits of autism such as echolalia, mutism, head-banging, and spinning.

“the preponderance of inner life with an active turning-away from the external world” (Bleuler, 1951, p. 402).

Kanner (1943) described what he referred to as “infantile autism” in children who, he later stated, were unable to “relate themselves in the ordinary way to people and situations” (Kanner, 1944, p. 211). Around the same time, Asperger published his own accounts of children with similar but less “severe” characteristics, but his work received little attention in the English-speaking world until Lorna Wing published a paper in 1981 that piqued interest in it (Wing, 2005). An English translation of Asperger’s paper was subsequently published. The identification of a “different form” of autism that could be labelled Asperger’s syndrome served to introduce the concept of autism as a spectrum of disorders (Wing, 2005).

Some, including Kanner, suspected that autism was related to bad parenting and blamed mothers for their children’s autism based on notions that it was caused by a lack of warmth and affection (the “refrigerator mother” hypothesis) (Bettelheim, 1955; Kanner, 1944). It was therefore advised that children be separated from their mothers during treatment (Bettelheim, 1955). Decades later, as behaviorists began to develop ABA, they advocated for family involvement rather than parent-blame and child-removal, leading to strong support from parents. (Kirkham, 2017).

The diagnosis of autism has evolved dramatically. The first edition of the *DSM* was published in 1952 and mentioned autism only as a symptom of schizophrenia; the second edition retained the association between autism and childhood schizophrenia (Autism History Project, n.d.). It was only in 1980 that the *DSM-III* listed “infantile autism” as a diagnosis distinct from schizophrenia, including it within a new category of pervasive developmental disorders with diagnostic criteria related to a “lack of social responsiveness” (Rosen et al., 2021). This was a major advance, but several problems were quickly identified. One was that a diagnosis required meeting all of the criteria, making it inflexible. Another was that it was oriented to presentation in very young children (Rosen et al., 2021). The *DSM*'s 1987 revision made serious changes in an attempt to address these concerns; "infantile autism" was renamed "autistic disorder," in recognition of the need for an approach that could be used across ages (Rosen et al., 2021). Additionally, the criteria were expanded and divided into three domains related to social interaction, communication, and restricted interests/repetitive movement. Under the *DSM-III-R*, an individual needed to meet only eight out of the 16 possible criteria to qualify for a diagnosis (Rosen et al., 2021). In the *DSM-IV,* the diagnosis retained the three domains, and it also included several subcategories. The inclusion of Asperger's disorder was possibly the most controversial change (Rosen et al., 2021).

The *DSM-5*, released in 2013, made more significant changes to autism as a diagnosis, amid debate and some opposition (Buxbaum & Baron-Cohen, 2013; Young & Rodi, 2014). The *DSM-5* merged the autistic disorder diagnosis with all other subcategories — Asperger's disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), Rett's disorder, and childhood disintegrative disorder — to create the autism spectrum disorder (ASD) diagnosis. The WHO made a similar change in its most recent revision to the International Classification of Diseases (ICD-11), which took effect in 2022 (Reed et al., 2019). Continued use of the diagnostic label "Asperger's disorder" is inadvisable not only because it no longer appears in the *DSM* or the ICD but also because of recent historical accounts of Hans Asperger and his work (Shalvey, 2021). These accounts have challenged previously accepted narratives of Asperger as someone who protected autistic children from Nazi eugenics programs, pointing to his likely complicity in the deaths of children deemed "unworthy" of life due to the severity of their disabilities (Czech, 2018). Beyond Asperger disorder's problematic eponym, these accounts highlight a more fundamental concern about dividing autism into subtypes that can be ranked based on the perceived value of people with each diagnosis (Hooge, 2019).

In any case, boundaries between the various subcategories in the *DSM-IV-TR* had not been well-defined and diagnostic clarity was poor (Rosen et al., 2021). Revisions to the *DSM-5*, released in 2022, made minor adjustments/clarifications but did not significantly alter the ASD diagnostic criteria (Bernhard, 2022).

2.1.2 Current Understanding of Autism

Many contentious points about autism remain unsettled, and modern understanding continues to evolve. As the prevalence of autism has increased, popular etiologic theories have sprung up. Such theories have sometimes emerged from research, most notably in the case of Andrew Wakefield's fraudulent study linking the childhood measles, mumps, and rubella vaccine to autism (Rao & Andrade, 2011). Despite overwhelming evidence that no link exists between autism and childhood immunizations, the myth persists (Gabis et al., 2022) and continues to contribute to the serious public health problem of declining vaccination rates (McKee & Bohannon, 2016). In addition, unsubstantiated theories about the origin of autism have led to the existence of many potentially dangerous products that claim to "cure" or treat it (Food and Drug Administration, 2019).

While the etiology of autism is far from fully understood, advances in technology have contributed to an improved understanding. Autism is heterogeneous not only in presentation but in etiology as well (Hyman et al., 2020); however, research suggests that strong genetic effects are involved, with heritability estimates between 64 and 91 percent (Tick et al., 2016). Etiologic evaluations are available and sometimes offered to families upon diagnosis; genetic testing can potentially lead to early detection of common comorbidities that pose a threat to the child's health (Hyman et al., 2020). However, the genetic factors involved are still not well understood, nor is the influence of environmental exposures and other factors (Hyman et al., 2020).

2.1.3 Autism Rights Movement and Neurodiversity

Allistic parents of autistic children were often at the helm of early advocacy efforts. In part, this was reactionary. The rhetoric of "refrigerator mothers" who were the cause of their children's struggles shifted to a new formulation of "warrior-hero" mothers who were the solution (Sousa, 2011). This resulted in an archetype that positioned parents as amateur-experts who were expected to act as champions to obtain the resources and support that their children needed (Sousa, 2011). Like most rhetoric about caregiving, the language is often gendered, from "refrigerator mothers" to "autism moms," but fathers also tend to see themselves as advocates who must fight for the resources that their autistic children need (Burrell et al., 2017).

Parent-led advocacy centered the families of autistic people and generally hinged on the assumption that autistic people's needs/concerns were identical to their caregivers'. During the 1990s, however, an autism rights movement emerged within the context of the broader disability rights movement. This social movement focused on centering the needs and goals of autistic people. In general, this precluded searching for a cure, which allistic advocates tended to prioritize (Sinclair, 1993). As autistic adults began to organize and advocate for themselves, they also started to form organizations that conformed to the disability rights motto of "nothing about us without us," such as Autism Network International (Kapp, 2020b). The concept of neurodiversity, and the political movement surrounding it, emerged from this. The first recorded use of the word *neurodiversity* is usually attributed to Judy Singer (1998), and many credit journalist Harvey Blume (1998) with introducing it to a mainstream audience. Those tracing the history of the neurodiversity movement, however, also point to the concept's origins in Jim Sinclair's 1993 speech, "Don't mourn for us." In it, Sinclair (1993) outlined a principle that remains at the center of this movement: "Autism is a way of being. It is not possible to separate the person from the autism."

Since that time, the word neurodiversity has come to refer to all possible variations of neurological and cognitive functioning. Those who fall within the bounds that society expects are branded as *neurotypical*, and those who fall outside the bounds are branded as *neurodivergent* (Kapp, 2020b). Neurodivergence, then, includes but is not limited to autism. The movement advocates for neurodivergent people's rights, especially inclusion and autonomy (Kapp, 2020).

In parallel, autism advocacy efforts by parents and other allistic people continued to focus on eliminating autism or mitigating its symptoms by searching for cures and more effective treatments. The search for a cure existed in a larger context of autism-as-tragedy narratives (Kurchak, 2015). It cast parents of autistic children as martyrs who were victims of their child's autism. Such narratives rarely considered the perspectives of autistic children and even more rarely recognized the existence of autistic adults. Autistic self-advocates have generally opposed both the narratives of tragedy and the goal of curing autism. This means that they are often in conflict with autism organizations.

Of note, autistic self-advocates tend to oppose Autism Speaks, one of the most influential autism organizations in the U.S. (Silberman, 2015; Willingham, 2013). Autistic adults' criticisms of the organization are numerous, but they mostly center around its autism-as-disease rhetoric and historical resistance to including autistic people in leadership roles (Robison, 2020).

Organizations such as Autism Speaks may be aligned with parents and families, but such groups have often rejected or ignored the opinions of autistic people themselves (Robison, 2020).

Conflict between caregivers of autistic children and autistic adults persists, especially online, sometimes even when the caregivers are themselves autistic (Coffey, 2021). Caregivers of autistic children whose disabilities prevent them from communicating for themselves may feel they are in the best position to speak about and for their children. Autistic adults tend to disagree with that position (Coffey, 2021), but a common criticism of the neurodiversity movement is that it does not consider people who are severely affected by their autism. The debate about appropriate autism interventions is at the heart of this conflict, and ABA, being the most common intervention, is a frequent point of contention.

2.2 Applied Behavior Analysis

The science of behavior analysis involves three domains: philosophy (behaviorism), basic research (experimental behavior analysis), and applied research (applied behavior analysis/ABA) (Cooper et al., 2020). Behavior analysis is concerned with the identification of functional relationships between the environment and behavior (McSweeney & Murphy, 2014). ABA is based on principles of operant conditioning. Operant conditioning posits that behaviors are learned based on responses from the environment. Its core constructs are reinforcement and punishment (McSweeney & Murphy, 2014). *Reinforcement* is anything that makes a behavior more likely to occur in the future, while *punishment* is anything that makes a behavior less likely. Both reinforcement and punishment can be either positive or negative. In common understanding, the use of the terms can be a source of confusion; however, in operant conditioning, *positive* simply refers to something being added to the environment, whereas *negative* refers to something being taken away. In common usage, for instance, “negative reinforcement” may be used to describe punishment, but in operant conditioning, it specifically refers to the removal of an aversive, that is, the removal of something that is unwanted. If the volume from a television is too loud, a child could ask their parent to turn it off; if the parent does, this is an example in which the behavior “asking for what they want” has been negatively reinforced. The child will be more likely to ask verbally in the future rather than using other options such as screaming or crying.

In addition to reinforcement and punishment, the concept of *extinction* is important. Extinction refers to the process of eliminating a behavior that was previously reinforced by removing the reinforcer. In ABA, this strategy is often used for behaviors that have been deemed attention-seeking. The idea is that a child’s undesired behavior (e.g., screaming) has been inadvertently reinforced (e.g., by a parent paying attention to the screaming child). The prescribed remedy is to remove the reinforcer of attention by ignoring the child instead of responding. Extinction can also occur in the opposite way, as when a previously punished behavior is no longer punished, and so it increases (McSweeney & Murphy, 2014). Extinction is often discussed alongside the concept of *extinction bursts,* in which there is an initial expected increase in the frequency and intensity of the undesired behavior until the child learns that the reinforcement will not be forthcoming. In the case of the child screaming for attention, this could mean that, temporarily, the child screams more often and more loudly.

Discussion of ABA as an intervention or therapy can be confusing because “applied behavior analysis” more precisely refers to the science from which various interventions are derived. These interventions are sometimes collectively referred to as “ABA therapy,” but they are often just known as ABA. There is no singular ABA, but numerous programs and methods are based on ABA (Keenan et al., 2015). Throughout this thesis, "ABA" refers to the entire collection of ABA-based autism interventions. ABA-based methods have been used in many different ways, but ABA remains strongly associated with its use as an intervention for autistic children (Dillenburger & Keenan, 2009).

ABA-based methods that are used with autistic children include early intensive behavioral intervention (EIBI), discrete trial training (DTT), pivotal response training (PRT), and verbal behavior intervention (VBI). ABA programs often use a combination of methods.

EIBI programs begin at a young age, last for multiple years, and are recommended for up to 40 hours per week (Reichow et al., 2018). DTT refers to a specific technique that is used to teach skills. In DTT, the practitioner breaks a task into smaller steps, guides the child's behavior, and repeatedly reinforces the behavior before moving to the next step (T. Smith, 2001). PRT focuses on natural reinforcement to increase an autistic child's motivation and self-management skills (Autism Speaks, n.d.-b), and VBI uses the principles of ABA with the goal of teaching a child communication and language skills (Autism Speaks, n.d.-c).

ABA looks at the "ABCs" of behavior, which stands for antecedent, behavior, and consequence. The antecedent is what happens just before a particular behavior, the behavior is the child's response, and the consequence is what happens after the behavior (Pratt & Dubie, n.d.). ABA's purpose is to manipulate the environment both by introducing artificial antecedents (*cues* to a behavior) and by changing the consequence. ABA focuses on skill acquisition and behavior reduction (Meadows, n.d.). It also heavily emphasizes data collection and measurement. ABA is ubiquitous as an autism treatment in the U.S., but it is used much more rarely in other countries (Keenan et al., 2015).

2.2.1 Development of ABA

Ole Ivar Lovaas is sometimes regarded as the “father” or a “pioneer” of ABA, at least as it is used with autistic children (Lovaas Center, n.d.-a; Smith & Eikeseth, 2011). Lovaas’s legacy is controversial at best, but one ABA-based intervention approach still bears his name and follows the methods that he laid out in his research (Lovaas Center, n.d.-b; Lovaas Institute, n.d.). This approach is characterized by its intensity (a recommended 35 to 40 hours per week) and its use of DTT. The Lovaas method is intended for use with very young children, ideally under the age of four (Lovaas Center, n.d.-b), and it is the blueprint for other EIBIs. However, Lovaas was not the first to use operant conditioning with autistic children. The development of operant conditioning in general is attributed to B.F. Skinner, and Lovaas was likely influenced by others before him who used these techniques with autistic children (e.g., Ferster, 1961). Lovaas studied under Sidney Bijou, who coined the term *behavior analysis* (Kirkham, 2017).

Lovaas remains the most well-known (and controversial) figure associated with the development of ABA, likely for two reasons. One is that he published an influential follow-up study that described almost half of the children in the treatment group as having “recovered” from autism (Lovaas, 1987). Despite whatever issues this study had (Schoneberger, 2006), these results became widely accepted as proof of ABA’s effectiveness and contributed enormously to its subsequent popularity (Kirkham, 2017).

The other likely reason for Lovaas’s infamy is that he gave several interviews in which he described the use of physical aversives, including electric shock, in his program. Lovaas was not the only person in his field at the time to use physical punishments; he was not even the only one to use electric shock on autistic children (Kirkham, 2017). However, he was the one whose research project was profiled by a magazine and illustrated with full-page photos of child abuse

(Moser, 1965). Another article described Lovaas as “a poet who keeps a paddle in the corner of his office and shocks small children” (Chance, 1974, p. 8). In the accompanying interview, Lovaas delivered a quote that dehumanized autistic children and remains strongly associated with him:

> *You see, you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense — they have hair, a nose and a mouth — but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person (Chance, 1974, p. 76).*

Despite this, many parents of autistic children saw Lovaas as a heroic figure (Kirkham, 2017). His attitude toward parents stood in sharp contrast to the prevailing attitude that parents should be blamed for their children’s autism. In the same interview, he made this position clear, saying, “Instead of blaming the parents, excluding them from treatment, and alienating them from their children, we bring the parents in on the treatment process” (Chance, 1974, p. 76). Moreover, Lovaas offered a treatment that gave parents hope for their children’s futures.

Throughout the 1990s and beyond, support for ABA was based on not just academic literature that showed its effectiveness but also narratives about children who were said to have recovered from autism. Since the publication of Lovaas’s (1987) follow-up study, discourse about ABA has been characterized by this notion of recovery and the idea that autistic children might become “normal” (Broderick, 2009). This discourse presents *hope* and sets it in opposition to *hopelessness*; the possibility of recovery is offered in contrast to the vision of a doomed life that an autistic child might otherwise lead (Broderick, 2009). Lovaas himself defended his harsh methods by stating that the use of physical punishments was preferable to a lifetime of institutionalization (Kirkham, 2017).

Many parents shared their families’ stories and credited ABA with helping their children recover from autism. These narratives, such as Catherine Maurice’s (1994) account, helped to elevate ABA above all other autism interventions. Even in more recent years, stories about children who "beat autism" have continued to be used in support of ABA, though often with more recognition that the results may not be so dramatic for all children (Padawer, 2014). In these cases, proponents have defined recovery as no longer meeting the diagnostic criteria for autism, so it is an important sidenote that the *DSM-5-TR* now explicitly states that symptoms "may be masked by learned strategies in later life" (APA, 2022).

2.2.2 ABA in the Present

ABA remains a popular autism intervention in the U.S. ABA is, perhaps, an effective method by which to decrease unwanted behaviors and increase behaviors that are considered prosocial (Rodgers et al., 2021). Other reviews have noted gains in adaptive skills as well as intelligence test scores (Peters-Scheffer et al., 2011; Reichow et al., 2018). Proponents use this literature to claim ABA as the only evidence-based treatment for ASD, emphasizing that hundreds of studies support its effectiveness for skill development (Autism Science Foundation, 2021). Regardless of this effectiveness, autistic self-advocates have criticized both ABA's methods and its goals (Kirkman, 2017). ABA supporters tend to disagree with these criticisms, however, noting that ABA-based approaches have changed over the decades and that its goals are individualized to each client and family (Autism Science Foundation, 2021).

The Behavior Analyst Certification Board (BACB) was founded in 1998 and is the primary certification body for ABA practitioners (Behavior Analyst Certification Board, n.d.-a). ABA professionals can become Board Certified Behavior Analysts and practice independently with either a master's or doctoral degree (BCBA or BCBA-D) (Behavior Analyst Certification Board, n.d.-c). With a bachelor's degree, it is possible to become a Board Certified Assistant

Behavior Analyst (BCaBA), which is a mid-level practitioner (Behavior Analyst Certification Board, n.d.-b). Additionally, anyone who is at least 18 years old, has a high school diploma, receives 40 hours of training, and passes an exam can receive a paraprofessional certification as a Registered Behavior Technician (RBT) (Behavior Analyst Certification Board, n.d.-e). RBTs work directly with the child under the direction of a higher-level practitioner. Many present-day practitioners receive these certifications, but not all of them. In the U.S., a growing number of states have adopted laws that require ABA practitioners at some or all levels to be licensed or certified, but 16 states still have no requirements (Behavior Analyst Certification Board, n.d.-d).

2.2.3 Criticisms of ABA

Criticisms of ABA call into question its status as a well-established, evidence-based method for autism intervention. Many meta-analyses and systematic reviews, some of which are used to demonstrate the effectiveness of ABA, actually show mixed or moderate results (Reichow et al., 2018; Rodgers et al., 2021; Su Maw & Haga, 2018). It is unlikely that the dramatic 47 percent recovery rate found by Lovaas (1987) will be replicated. Another criticism of the research is a failure of authors to accurately report conflicts of interest, of which there appear to be many (Bottema-Beutel, Crowley, et al., 2021a). Other criticisms include an overreliance on single-case designs, a lack of randomized controlled trials, and accusations of misuse of meta-analyses in order to amplify poor quality research (Dawson & Fletcher-Watson, 2021).

The issue of undisclosed conflicts of interest is especially important when published articles provide support for an intervention that can cost between $40,000 and $60,000 per year (Dawson & Fletcher-Watson, 2021; National Conference of State Legislatures, n.d.). An emerging body of criticism centers around what is sometimes referred to as the *Autism Industrial Complex (AIC)*, positioning ABA and autism interventions more generally within the context of capitalism. These critics question ABA as an industry and consider profit motives (Broderick & Roscigno, 2021). In addition to noting conflicts of interest in the research, AIC-related criticism also tends to emphasize state-level lobbying efforts in favor of legislation to increase funding for ABA services (Broderick & Roscigno, 2021).

ABA research has also been criticized for a lack of reporting on adverse effects, indicating a failure to consider potential risks of the intervention (Bottema-Beutel, Crowley, et al., 2021b), although this is also a larger criticism of most research into non-pharmacological interventions (Papaioannou et al., 2021). Ethical criticisms, meanwhile, sometimes assert that ABA is an abusive intervention (Sandoval-Norton et al., 2021; Sandoval-Norton & Shkedy, 2019), an accusation that ABA proponents deny (Gorycki et al., 2020)

Additionally, critics cite opposition to the historical use of aversives and Lovaas's connection to the development of conversion therapy targeting gender non-conforming boys (Gibson & Douglas, 2018; Rekers & Lovaas, 1974). ABA proponents often argue that modern ABA has shifted away from the practice of using physical punishments, or even punishments in general (Autism Science Foundation, 2021). However, critics of ABA point to the use of electric shock as punishment at the Judge Rotenberg Center (JRC) in Massachusetts, which continues even in 2022. Although the Food and Drug Administration (FDA) issued a ban on the graduated electronic decelerator (GED) device that JRC employees use, a federal appeals court subsequently overturned this ban (Morrison, 2021). Autistic advocates also note that the shock device is not the only means by which JRC residents are abused, nor is that facility the only one to abuse disabled people (Neumeier & Brown, 2020). The Association for Behavior Analysis

International (ABAI), which is strongly associated with ABA, has not condemned the JRC and has hosted JRC representatives as event speakers in recent years (Autistic Self Advocacy Network, 2019).

When autistic adults criticize ABA, they do not tend to focus on ABA's effectiveness or lack thereof. Instead, self-advocates generally criticize the aims of ABA treatment. They often draw on the neurodiversity paradigm that considers autism to be a difference rather than a deficit and argue against the goal of changing autistic people's behavior to make them appear more neurotypical (Ask an Autistic, 2019). For instance, autistic self-advocates often note that ABA treatment goals can include the elimination of *stimming* behaviors. *Stimming* refers to what is sometimes called self-stimulatory behavior or stereotypy, which is included in the ASD diagnostic criteria as "stereotyped or repetitive motor movements, use of objects, or speech" (American Psychiatric Association, 2022). Examples of stimming behaviors include hand-flapping, bouncing, rocking, spinning, and repetitive squealing. Some stims may be unsafe or self-injurious, but most are not, and ABA critics argue that ABA targets even harmless stims for elimination, on the grounds that they are disruptive, are not socially acceptable, or interfere with learning (Cunningham & Schreibman, 2008; Leaf et al., 2021). Autistic adults tend to report that stimming behaviors are natural movements for them and are ways of expressing emotion, self-regulating, and relieving sensory overwhelm (Kapp et al., 2019), so self-advocates generally oppose the goal of suppressing non-harmful stimming (Ask an Autistic, 2019).

A recent large survey asked respondents whether they agreed with the statement, "I support the use of ABA for autistic children" (Bonnello, 2022). Nearly 90 percent of autistic respondents answered that they "disagreed" or "strongly disagreed," including 72 percent of the autistic respondents who had personally experienced ABA. Some agencies that are not autistic-led dismiss these criticisms while emphasizing the importance of evidence-based interventions (e.g., Autism Science Foundation, 2021). In news and entertainment media, stories about ABA sometimes include a cursory overview of autistic self-advocates’ criticisms, but this can be overwhelmed by a much greater emphasis on the opinions and experiences of allistic caregivers and professionals. For instance, a self-advocate’s arguments were granted a few paragraphs in a very long article about children recovering from autism via ABA, and these paragraphs were sandwiched between ABA success stories (Padawer, 2014).

Despite several decades of anti-ABA advocacy from autistic adults, the academic literature has neglected to consider autistic experiences of ABA until very recently. Even with more movement toward participatory research methods and the development of new frameworks to guide the process (Fletcher-Watson et al., 2021; Nicolaidis et al., 2019), little of this research has focused on childhood interventions.

One recent study found ABA exposure to be associated with higher rates of self-reported post-traumatic stress symptoms (PTSS) (Kupferstein, 2018). This study relied on self-reported data, and an evaluation of it noted several methodological weaknesses (Leaf et al., 2018), but these findings still suggest a need for careful consideration of possible long-term negative impacts from ABA. Another study interviewed ABA-exposed autistic adults and found themes of hidden harms (McGill & Robinson, 2020). This too highlights the need for more focus on possible long-term effects of early childhood interventions.

Further ABA research that examines the perspectives of autistic people is needed. Long-term outcomes of ABA are not well understood, especially not ones that involve autistic people’s internal experiences, and it is possible to consider such impacts only from the perspective of the person who received the intervention. Autistic people, as consumers of ABA services, are the most important stakeholders and also the ones most likely to be overlooked. Understanding autistic adults' perspectives on ABA will help to contextualize approaches used with autistic children now and in the future.

2.3 Theoretical Considerations

Much of the conflict about ABA is rooted in theoretical perspectives on disability. The various models of disability represent, at the most basic level, the framing for different understandings of autism. While many broad models of disability exist, it should also be acknowledged that not all potentially disabling conditions are alike, and many models focus on a more specific target rather than all disability (Berghs et al., 2016). It is also important to consider the theoretical basis for ABA and how this interacts with different models of disability.

2.3.1 Models of Disability

The *medical model* of disability has long been the default and is often the unstated theoretical framework through which disabilities, including autism, are viewed. This framework understands disability as an impairment that results from a deficit or problem within the individual; disability is caused by an "abnormality" that should be "fixed" as much as possible, whenever possible (Berghs et al., 2016). The *social model* of disability rejects this idea and distinguishes between impairment and disability. Under the social model, disability is a social oppression resulting from ableism: unremoved barriers, discrimination, and prioritization of nondisabled people's needs (Berghs et al., 2016). Disability is created by the gap between what someone with an impairment needs and what their society is willing to offer them.

While some in the neurodiversity movement prefer not to identify as disabled, others endorse the notion that they are disabled under the social model due to living in a society that does not accommodate their needs (Berghs et al., 2016) For instance, the conception of autism has generally focused on deficits within the individual. Social-communication difficulties, under the medical model, are deficiencies that exist within the autistic person. Challenges to this perception, however, can be based in the social model. The autistic person's "lack of insight" into a neurotypical person's mind can be viewed as a deficit that belongs to the autistic person alone *or* it can be viewed as a bidirectional challenge, given that neurotypical people also tend to lack insight into autistic people's minds (Milton, 2012). Recent evidence supports the latter characterization (Crompton et al., 2020; Davis & Crompton, 2021), and if this is the case, these traits of autism can be viewed within the social model as disabling only because the onus is on the autistic person to bridge the gap of understanding. It is the expectations of the society, not the condition itself, that makes this a disabling experience.

Critical Autism Studies (CAS) relies on influences from Critical Disability Studies, as well from the social model of disability. Though the precise definition of CAS is evolving and remains contested, one key feature is its critical investigation of the power dynamics at work in discussions about autism (Woods et al., 2018). Additionally, CAS calls on autism research to question definitions of autism that rely on deficits/impairments and to consider the ways that biology and culture can intersect to create "disability" (Woods et al., 2018)

2.3.2 Behavior Modification

The principles of behavior modification used in ABA come from the philosophy of behaviorism (McSweeney & Murphy, 2014). ABA uses the constructs of operant conditioning — reinforcers to increase desired behavior, punishments and extinction to eliminate undesired behavior — to shape the behavior of autistic children (McSweeney & Murphy, 2014). The grander underlying theory, however, is that the child’s behavior is the problem, and that the child’s behavior can be modified by making small, deliberate changes to the environment that teach the child to behave in ways that are different from the ways in which they are naturally inclined to behave. If the problem is the child’s behavior, then modifying the child’s behavior obviously solves the problem. However, if the actual problem is that the child is in distress, and the behavior is an expression of that distress, then changing the child’s behavior has not actually resolved the problem for that child, only hidden it from others.

The theoretical framework behind the use of behavior modification as an intervention or treatment for autistic children cannot easily coexist with a framework based on the social model of disability or with CAS. Rather, an intervention based in the social model might seek to determine what in the environment is causing the problem and then eliminating it. In contrast, behavior modification approaches often condition the child to tolerate discomfort by rewarding them for not outwardly reacting to it, regardless of whether the child’s distress is lessened. Likewise, the use of behavior modification techniques to teach a child adaptive or prosocial skills does not integrate well with the social model or CAS. Instead, these techniques align with a model that sees autism as a set of deficits to be fixed. If the goal of ABA is to transform an “abnormal” child into a “normal” child, it can coexist only with the medical model of disability (Shyman, 2016). Autism treatment, then, is viewed through a positivist lens that does not question whether the goal of normalcy is appropriate or desirable but merely seeks to uncover objective truth about which treatments are most effective for achieving that goal (Shyman, 2016). While it may be possible to reconcile behavior modification generally and ABA specifically with the social model of disability, this is a challenging task.

2.4 TikTok and the Autistic Community

The internet has helped to facilitate much of the autistic community's organization and advocacy over the past several decades (Kapp, 2020a). Conversation and connection between autistic people often happen on social media, blogs, and other online spaces. Researchers have begun to recognize the usefulness of these sources of data (Bellon-Harn et al., 2020; Harmens et al., 2022; Welch et al., 2020). On many social media platforms, autistic people use the phrase or hashtag "actuallyautistic" as a way to identify autism-related content produced by autistic people (Eartharcher, 2017).

TikTok is a newer social media platform, first appearing outside of China in 2017, but among its users is a robust community of autistic creators who make videos on a variety of autism-related topics. TikTok attracts a younger audience than many other social media platforms, and out of its estimated 80 million U.S. users, about 80 percent are between the ages of 16 and 34 (Wallaroo, 2022). While TikTok is clearly very popular with adolescents under the age of 18 (Wallaroo, 2022), autistic creators tend to be young adults or older, and many accounts that feature younger autistic people are run by their caregivers (Nast, 2021). The most popular autistic creators often have a presence across several social media platforms; on TikTok, some of these creators receive millions of views on their videos (Nast, 2021). The videos that autistic

TikTok creators share have the potential to provide rich information about their experiences and perspectives.

TikTok is known for its short-form video content, originally allowing videos no longer than 15 seconds. The platform has since extended its maximum length, first to one minute and then to three minutes. TikTok also includes features known as “stitches,” “duets,” and “video replies,” all of which allow creators to respond to other users in a video. Creators can affix their response to the end of another user’s video (stich); record a video that appears on the screen beside another user’s video (duet); or make a video in response to another user’s text comment (video reply). Autistic creators use these features to engage in conversation and debate within and outside of the community.

TikTok videos can take a variety of forms. Creators can make videos with audio taken from other users; such an audio could be a short clip from a song, dialogue from a movie or television show, or a user’s original content. Videos can also include on-screen text, which may or may not include captions of the creator’s speech, and it is also possible to use a screen reader feature that will read on-screen text aloud. These features make the creation of TikTok videos accessible to autistic people who are sometimes or always nonspeaking.

TikTok also allows for the inclusion of a short text description and accompanying hashtags. TikTok users typically navigate the application via their “For You” page, which uses a sophisticated algorithm to determine what videos it believes the user would like to see and begins to play them as soon as the user opens the mobile app. This set-up means that users can navigate the app without ever using hashtags, but most TikTok videos include multiple hashtags, which likely help the algorithm determine which users should see which videos (Anderson, 2020). It is also possible to view “trending” hashtags on the “Discover” page within the application. As on other social media platforms, autistic adults often use the “actuallyautistic” hashtag on TikTok to indicate that they are speaking from personal lived experience.

3.0 Methods

This study used qualitative methods to explore autistic adults' ABA-related perspectives as shared on social media. Specifically, the study collected and analyzed video content posted by autistic adults to the TikTok platform, as well as text-only posts made to public Facebook pages. Analysis was done using NVivo 1.6.1. Data collection and analysis were not distinct processes. TikTok videos were collected in batches of five, transcribed, and reduced using initial descriptive codes prior to collection of the next batch. Saturation for the TikTok videos was considered to have occurred when no new codes were generated by a batch of five videos. The procedure for sampling, data collection, and analysis was heavily informed by the methods described by Herrick et al. (2021).

3.1 Sampling and Data Collection

3.1.1 TikTok

A new TikTok account was created and used to collect videos. Most TikTok users interact with the platform via its mobile application, but for ease of data collection, all videos were identified and collected within a web browser. TikTok's navigation is designed for mobile devices, and some functionality is limited when using a browser, but this did not affect the ability to search for, view, and save videos.

Previous analyses of TikTok content have selected videos from a specific hashtag or hashtags (Herrick et al., 2021). Using this method, it is possible to view a list of all videos that use one particular hashtag. For the present study, however, it was important to locate relevant videos that were created by a specific population. While some videos listed under ABA-related hashtags (such as "appliedbehavioranalysis") were created by autistic adults, many were created by ABA practitioners, and many were unrelated to autism. Combining two hashtags as search terms appeared to be the best method to locate relevant content, so TikTok's search feature was used rather than looking at videos under a hashtag. Each search combined two terms, one related to autism and one related to ABA. Initial searches were for "autism + appliedbehavioranalysis," "autism + aba," and "autism + abatherapy." Appendix A shows a diagram of this entire process and the search terms used at each step.

Inclusion criteria were as follows:

- The video was on-topic and specifically discussed ABA as an intervention for autism.
- The video creator self-identified as autistic in the video or video description, in their profile, through their username (e.g., "[name].is.autistic"), or by using the "actuallyautistic" hashtag.
- A maximum of three videos were included for each creator.

The second criterion refers to *self-identification* rather than *diagnosis* because, due to the nature of collecting social media data, it was not possible to verify whether creators had a medical diagnosis of ASD. It is likely that at least some of the included creators do not have an official diagnosis since self-diagnosis is relatively common, especially for women and others who were less likely to receive medical diagnoses as children (Lewis, 2016; McDonald, 2020). Additionally, despite the focus on autistic adults, age was not used as an inclusion criterion because it was impossible to determine every creator’s age based on their videos and profile. Any creator with an apparent age under 18 (e.g., as listed in their profile) would have been excluded, but this did not apply to any of the videos that were identified.

Using the initial search terms, a total of 10 videos that met inclusion criteria were quickly selected, in order of their appearance in the search results. However, all 10 were from white or white-appearing creators. In an effort to increase the racial diversity of the sample, search terms were reconsidered at this point. It was possible to identity several hashtags commonly used by Black, Indigenous, and other autistic people of color. These were “blackautistic,” “brownautistic,” “bipocautistic,” “autisticpoc,” and “autizzy.” Searching for these terms alone returned many videos, but few were related to ABA. Each term was subsequently combined with each ABA-related search term. Purposive sampling of the results led to the selection of videos 11 through 15: three by Black creators, one by an Indigenous creator, and one by a white creator (which was included because it explicitly discussed race). The remainder of these search results, however, used only one of the two search terms as hashtags; that is, they were either made by an autistic person of color but unrelated to ABA, related to ABA but made by a white-appearing creator with no discussion of race, or not made by an autistic person. Because no more relevant videos could be identified using these race-specific hashtags, the initial search terms were used to identify the rest of the selected videos (16 through 66). Most of these videos were from white/white-appearing creators.

Videos were collected in batches of five, transcribed, and then reduced using initial descriptive codes. This process allowed for the assessment of informational redundancy as a way of determining data saturation (Saunders et al., 2018). The point at which no new descriptive codes were created from a batch of five videos was determined to be the appropriate time to end data collection, as the collected videos would be likely to represent the range of perspectives shared by autistic adults in TikTok videos at the time of collection.

Only two new descriptive codes were generated from the penultimate group of videos. The final batch included six rather than five videos. This was because one of the videos was not initially included due to not fully meeting inclusion criteria. The creator of this video did not identify as autistic in any of the ways listed above. Rather, the creator's profile described them as "possibly #autizzy[3]," which was taken to mean that the creator did not have an official ASD diagnosis but identified with autistic traits. During the process of initial coding for the final group, the exclusion of this video was reconsidered. It was ultimately included because the creator was the Black parent of a Black autistic child, an underrepresented viewpoint in this analysis. Additionally, the creator's expression of possible self-diagnosis could not be justified as a reason to exclude it, given the likelihood that other included videos were created by self-identified autistic adults without an official diagnosis.

This video, and one other in the final group, generated three new descriptive codes. This should have meant that additional videos be collected, given that data saturation was not reached according to predetermined criteria. However, flexibility was considered necessary at this point. In one of the videos that generated new codes, the creator shared a Facebook post made by a Black autistic parent of Black autistic children. This video, along with the one mentioned in the previous paragraph, yielded new codes but also uncovered a richness of data about race and nuance that had not been found in the TikTok videos until this point. Considering the difficulty of locating ABA-related videos from Black, Indigenous, and other people of color (BIPOC)

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[3] "Autizzy" refers to a hashtag coined by a Black autistic creator for use by other Black autistic people when discussing their experiences.

autistic creators, the decision was made not to collect additional TikTok videos, as these would be unlikely to offer new information or richer explorations of ABA, nuance, and race.

The referenced Facebook post was located, and it was analyzed separately from the video in which it had been shared. The descriptive codes generated from analyzing this full post were noted to be very different from most of the TikTok videos, so it was decided to further explore these issues via Facebook instead of TikTok.

Three TikTok videos were ultimately excluded from the analysis. In one case, the creator had posted a new video stating that she no longer supported the views that she had expressed in the previously collected video. To better reflect her perspective, the older video was excluded and replaced with the newer video. Two other videos, both by the same creator, were excluded because the creator changed their account settings to “private” prior to analysis.

The analysis included 63 videos that were posted by 47 unique creators. Appendix B shows the characteristics of each TikTok creator and details about each video. Videos are identified as “TT” followed by a number. Videos were not renumbered after excluding three, so they are identified as TT1 through TT66.

Data were collected by downloading the video and taking a screenshot of the video’s information. That information included the date posted, hashtags used, text of video description, username, and the top several comments. An additional screenshot was taken of the creator’s TikTok profile, which included whatever information the creator chose to share, often pronouns, race, age, and identification as autistic. These files were linked together through matched numbering.

One video was posted to the platform on February 17, 2020; all others were posted between January 18, 2021, and February 10, 2022. Collection of these videos occurred between November of 2021 and February of 2022.

3.1.2 Facebook

The above-mentioned Facebook post shared in a TikTok video was the first one collected. The decision to include this full post as its own separate case was made because it raised new issues that had not been uncovered in the TikTok videos and because it added depth and richness. The new descriptive codes generated from this post all related to race, so it was decided to explore these issues further using Facebook, given the difficulty of locating ABA-related TikTok posts by BIPOC creators.

Time constraints did not allow for extensive sampling of Facebook posts, so a small number of posts were selected for their ability to provide insight into this specific line of inquiry. These posts were identified via convenience sampling. In the comment section of the first Facebook post, one commenter provided a link to a post that listed “BIPOC autistic Facebook pages to follow.” The list did not appear to be in any particular order, so Facebook posts were located by going down the list and searching Facebook for each page name together with “aba,” then filtering the Facebook search results to show only “posts.” For pages that returned a relevant result, the post was collected and reduced using initial descriptive codes. Only one post per page was included; one search returned several posts, and the one that appeared first in the search results was used. This process identified three additional Facebook posts. Two of these posts generated one new code each, and the third generated no new codes. More extensive sampling of

Facebook posts could have yielded new information and greater depth, as it is unlikely that these posts represent the range of ABA-related perspectives among BIPOC autistic creators on Facebook. However, these posts still allow for greater exploration and provide insight into a dimension of the research question that the TikTok videos alone do not.

A total of four Facebook posts, by four different creators, were included in the analysis. Appendix C details the characteristics of each Facebook creator and post. The posts are identified as "FB" followed by a number (FB1 through FB4).

Facebook posts were copied and pasted into a document along with the name of the page, dated posted, and the text of the page's "About" section. All four were posted between December 31, 2021, and January 21, 2022, and collected from Facebook in February of 2022.

3.2 Data Analysis

Reflexive thematic analysis was used to interpret the data. This approach worked well for the present research question because it recognizes the inherent subjectivity of qualitative research and the need to reflect on assumptions; allows for a balance between theory-driven and data-driven analysis; and emphasizes flexibility in coding as the researcher's understanding deepens throughout the process (Braun & Clarke, 2021). The unit of analysis was the video or post. Some creators had two or three videos included, while others had only one, but different videos by the same creator sometimes expressed very distinct points.

Data were analyzed using an inductive process with no predetermined codes, but codes were developed into themes based on an interpretation of their shared meaning that was informed by theoretical assumptions. A file was created for each TikTok video that included the following:

date posted, length of video, whether it was a response and what type, race of creator, age of creator, text of video description, and hashtags used. These files also included the username of the creator, which was later removed but used initially to link multiple videos that were from the same creator.

Each video was viewed at least three times to establish familiarity with the content. All audio was transcribed into the file; depending on the video, this included the creator's speech, lyrics to songs used, and/or dialogue clips overlaid onto the video. On-screen text was also typed into the file. In videos where the creator spoke, if on-screen text appeared that was different from the words spoken, both were noted. If on-screen text was simply open captioning of audio for accessibility, this was noted but not typed twice, as long as the spoken and written text did not have significant differences. Non-speech sounds (e.g., background music) were noted, as well as use of song lyrics or dialogue clips for communication. The file also included notes about physical space in the video, such as the creator's positioning and objects in the background. The creator's location was noted, if identifiable. When notable, the creator's movements were also included, and visual elements of the video (e.g., camera angle changes, use of graphics) were as well. Any miscellaneous details and context were also noted in the file.

As mentioned above, first-pass coding was completed in groups of five videos, using initial descriptive codes to assess data saturation. After all videos and posts were collected and first-pass coding was complete, codes were reevaluated. Similar codes were merged, and rarely used codes were reconsidered. From this a codebook was generated. Next, codes were grouped together based on apparent similarities. These groups were reviewed and refined several times. Eventually, four major themes were identified, and code groups (subthemes) were placed within them. Themes and subthemes were then named. A few codes did not fit well within any subtheme group, so they were placed directly beneath a theme. The names of themes and subthemes were then modified to better reflect all of the data that they included.

3.3 Ethical Considerations

This research was determined to be exempt from review by the Institutional Review Board due to the use of only publicly available information and lack of interaction with the individuals whose data was used. Nonetheless, ethical concerns were contemplated and decisions were informed by ethical guidance for internet research (franzke et al., 2020).

The two most important considerations were the issues of *consent* and *privacy*. The data were publicly available, which can be interpreted as the creators having no expectation of privacy. However, there are different levels of privacy expectation on social media, even for public content. A user does not typically expect a public post on their personal Facebook page to be viewed by millions of people, for instance.

For the TikTok videos, which were all public, there was assumed to be a low expectation of privacy. This is due to TikTok's algorithm and the way that users interact with the application; users are shown videos on their "For You" page and these are not limited to people that they know or accounts that they follow. The expectation when posting a public video to TikTok is that it will appear on the "For You" page of strangers. Users can adjust their privacy settings if they do not want this. A personal Facebook post, even a public one, comes with a slightly higher expectation of privacy. For this reason, the Facebook posts collected were all from public "pages" (which are more akin to blogs) rather than personal accounts.

Information about the characteristics of the individual videos and creators is available in the appendices and includes demographic characteristics that the creators chose to publicly share. However, in consideration of privacy, names/usernames have been removed. Images from the videos are also not presented here, as an additional privacy protection. For the Facebook posts, page names are also removed, but this thesis includes substantial quotations from these posts. It is therefore possible to locate the original posts by searching Facebook, which would identify the creator's page. However, the public nature of these pages (all of which are "followed" by thousands of users) is a good indication that the posters want, or at least do not mind, public consumption of their writing.

The issue of consent is also important, despite being assumed based on the public nature of the content. The user's agreement to the platform's terms of service is sometimes regarded as consent for research, but social media terms of service are long and filled with jargon, and it is very unlikely that the user read them before agreeing. This does not seem to indicate informed consent, and it is very unlikely that someone who posts on social media is even considering the possibility of their post being used in research. Another concern about consent in social media research is that the user lacks the ability to withdraw consent, given that they are unaware of being a research participant. Creators could change the privacy settings on a post or delete it altogether, but the researcher would not necessarily even be aware of this happening to a post they have already collected.

To help mitigate this concern within the present study, each creator's page was revisited immediately prior to beginning data analysis to check that the collected posts remained publicly visible. Based on this process, one video (TT20) was subsequently excluded from the analysis not because it had been deleted but because the creator had since posted a new video indicating that she no longer endorsed the expressed views and would “probably delete it” (TT64). In alignment with the creator’s clear preference, the originally collected video was excluded from analysis and the newer video was included instead. Two additional videos (both by the same creator) were excluded from the analysis because the creator had changed her account to private. This left a total of 63 videos that were used in the analysis.

4.0 Results

Sixty-three TikTok videos were analyzed, after removing the three excluded videos, and four Facebook posts were also analyzed. A total of 51 unique creators posted this content.

4.1 Characteristics of the Creators

As noted in the description of the sampling process, it was not possible to determine the age of every TikTok creator. TikTok allows a maximum of 80 characters for users' profiles, and many did not mention their age. Out of the 47 TikTok creators included in this sample, only 17 referenced their age. One of these merely referred to himself as an adult, and another stated that she was "20-Something." The 15 other creators who listed their age ranged from 20 to 36 years old. It was not possible to conclusively determine that all the other creators were adults. However, many referenced having jobs in fields such as social work, attending graduate school, or being the parent of a school-aged child. Such references indicated that they were probably over the age of 18, and no creators made references that could suggest they were under 18. None of the Facebook creators listed their age, but three out of the four identified as parents of autistic children in their "About" sections.

Seven of the videos were by creators who identified as Black in their profiles, videos, or with a hashtag; these were made by six unique creators. One creator, from whom one video was included, identified as indigenous; another identified simply as bipoc. The remainder of the TikTok creators either explicitly identified as white or made no mention of race. Two of the four

Facebook posters identified as Black, one as Indigenous, and one as brown Asian. Races are described here exactly as the creators identified themselves, including capitalization.

4.2 Characteristics of the Videos and Posts

The 63 TikTok videos ranged in length from four seconds to three minutes (the maximum length allowed by the platform), with a median length of 57 seconds. The Facebook posts ranged in length from 280 to 3076 words.

Most of the videos appeared to have been filmed in the creator's home or a very similar space. For some, the location was indoors but otherwise unclear from the background (e.g., a blank wall). A few videos were filmed outdoors or in a car, and one creator did not appear in their video at all. Table 1 shows an overview of some characteristics of the videos (see Appendix B for more details).

As noted above, TikTok offers several features that allow creators to respond to other users: duets, stitches, and video replies. Many of the videos selected for analysis were responses to other users using one of these features, and four videos included a screenshot or screen recording that displayed a comment/video to which the creator was responding. Responses to other users were categorized as disagreeing or arguing (most common), agreeing with or amplifying the user's message, answering a direct question in a positive or neutral way, or complicating a user's message by adding nuance (but without conflict).

Table 1 Overview of TikTok Video Characteristics (n = 63)

Video Length (seconds)	
Median (Range)	57 (4 – 181)
Location	
Home	48
Outdoors	3
Car	1
Unclear	10
User did not appear in video	1
Response to Another User	26
Duet	5
Stitch	2
Reply to comment	15
Response but no feature used	4
Disagreeing	11
Answering a Question	8
Agreeing/Amplifying	5
Complicating/Adding nuance	2
Used Background Music	17
Method of Communication	
Speech	36
On-screen text	22
TikTok audio	14
Dialogue	5
Song lyrics	9
Dancing/physical movement	9
Other	2
Style	
Addressed viewer	50
Addressed specific user	3
Dialogue with self	10
Used TikTok trend	14

The videos used a variety of communication methods and styles. Seventeen featured background music. In addition to speech, creators communicated using on-screen text, dialogue or song lyrics from TikTok audio clips, and/or dances or other physical movements. One creator used the "robot voice" of a screen reader to read out their on-screen text, and one used a still image that communicated her point. Nearly half of the creators communicated their message without ever speaking in the video.

Stylistically, most videos featured the creator looking toward the camera and addressing the viewer directly; creators addressed the viewer using all of the different communication methods: speech, on-screen text, physical movement, and lyrics or dialogue from a TikTok audio. A few videos were responses in which the creator directed their message to a specific user. Several used a "dialogue with self" conceit in which the creator acted the part of two (or more) separate characters having a conversation. This style involved changing the camera angle, the creator's position, and sometimes the creator's appearance to distinguish between characters. Some of these "dialogue with self" videos used the creator's own words, while others used dialogue or song lyric clips from a TikTok audio.

Several videos also used songs, other audio, or dances that could be identified as TikTok trends. These were audio clips or dances either currently or previously popular throughout TikTok. For example, this included use of the songs "All Eyes on Me" from Bo Burnham's comedy special *Inside* and "We Don't Talk About Bruno" from Disney's *Encanto*.

4.2.1 Hashtags

Hashtags were not analyzed because, while some clearly communicated perspectives on ABA (e.g., #abaischildabuse) or expressed activist goals (e.g., #banABA), others were simply used to denote the video's topic (e.g., #appliedbehavioranalysis). Additionally, some videos included hashtags from irrelevant marketing campaigns (e.g., #sharethemagic), as it is a common belief among TikTok users that this can increase a video's views (Sandler, 2020).

The most used hashtag was #actuallyautistic. For the data collection process, this hashtag served as an indicator that the creator was autistic. It was not used as a search term, but it appeared more frequently than hashtags that *were* used as search terms. The #actuallyautistic hashtag was used on 43 out of the 63 videos. Figure 1 shows a word cloud of the hashtags that creators used, illustrating just how frequently used #actuallyautistic was when compared to other hashtags.

Figure 1 Word cloud of hashtags used in the sampled TikTok videos

Other common hashtags included #autism, #abatherapy, #appliedbehavioranalysis, and #aba. Given that these were used as search terms, their high frequency is unsurprising. The most common hashtags were merely descriptive of the content and neutrally referenced autism or ABA. Of relevance, the seventh most common hashtag was #abaisabuse, a clear expression of anti-ABA perspectives, and an additional three videos used simply #abuse as a hashtag. See Appendix D for a frequency table of all hashtags used in the sampled videos.

4.3 Emerging Themes

Analysis of the TikTok videos and Facebook posts identified four major themes: (a) harms caused by ABA; (b) opposition to ABA as a field of practice; (c) the need for nuance in discussions of ABA; and (d) conflict in discussions of ABA. While most creators expressed criticism of and opposition to ABA, several also focused on the need to engage in discussions about ABA that consider the systemic reasons that caregivers choose ABA for their children. The identified themes and subthemes are displayed in Table 2.

The quotations presented in this chapter come from words spoken or audio used in TikTok videos, on-screen text in TikTok videos, TikTok video descriptions, and Facebook posts. If the creator did not indicate their pronouns, singular “they” will be used when referring to them. Quotations are copied or transcribed exactly as written or spoken; ellipses indicate places where they have been trimmed for brevity or clarity.

Table 2 Autistic Adults' Perspectives on ABA

Themes and Subthemes	Illustrative Quotation
Harms caused by ABA	
abuse	"Hi, I'm going to share my thoughts on ABA therapy. It's abuse!"
long-term effects	"It has observable negative impacts on adulthood."
anti-neurodiversity	"It's teaching autistic children to mask and act like neurotypical people."
failure to address root causes of behavior	"Changing the behavior does nothing for that distress."
Opposition to ABA as a field of practice	
ABA's disturbing history	"Now when it was created in the 1960s, the way Ivar Lovaas did this was by beating the children."
unacceptable methods	"Planned Ignoring is disgusting."
core problems with the science/profession	"The ABA done as intended is the kind causing the most harm."
for other people's benefit	"ABA does nothing except make the adult feel better."
Need for nuance in discussions of ABA	
ABA is a leaf, not a root	"ABA is not the problem. It is a symptom."
mixed feelings about ABA	"The hardest part is that, although ABA is an abusive practice, the people at the program loved me."
benefits of ABA	"We want them to be independent and have functional lives as adults."
parents are not the enemy	"And if parents and primary caregivers are not supported, they can't meet the needs of their autistic children."

Table 2 (continued)

Conflict in discussions of ABA	
ABA practitioners vs. autistic adults	“BCBAs, RBTs, and other bootlickers coming to defend their abusive practices”
‘autism moms’ vs. autistic adults	“Hello [air-quotes] ‘autism mom’. My healing journey is none of your business.”
autistic people are the experts	“Please listen to autistic people”
conflict among the autistic community	“I don’t experience disability as white disabled people do and y’all don’t get that.”

4.3.1 Harms caused by ABA

Most creators communicated the perspective that ABA is harmful to autistic people. Some of these perspectives referenced personal experiences of being exposed to ABA, some drew on the experiences of others that they had heard about, and some spoke more generally.

Abuse. Many creators talked about ABA as abuse and used the word “abuse” to describe ABA in broad, general terms:

> *Applied Behavior Analysis is abuse. Period. (TT10)*
>
> *I know ABA’s a abusive practice, we all know that. There were things that happened to me that weren’t right. (TT14)*
>
> *ABA is abuse backed ONLY by pseudoscience. (TT17)*
>
> *ABA is bad for society because that is considered abuse. (TT43)*
>
> *ABA therapy is child abuse. This has been proven by the experience of autistic people. (TT45)*

Creators also talked about ABA as abuse in relation to specific methods, practices, or incidents of which they were aware. One creator discussed seeing a video by an ABA practitioner that described a strategy that they used. This involved writing down any occasion on which the child failed to complete a task, waiting until the child asked to do something enjoyable, and then responding “I owe you a no” because of the child’s past failure. The creator described this as “literally a tactic that manipulatively abusive people use to coerce behavior.” They continued,

> *Like what in the fuck, when my own parents did that, they were told that they were committing psychological abuse. But it’s okay if you’ve got a [air quotes] “behavior modification therapist” title at the front of your name? Like no, no. … I’m literally disgusted because this person is advocating for child abuse. Literal child abuse. (TT46)*

Other creators mentioned abuse in the context of “old ABA” versus “new ABA.” They argued that a move toward gentler tactics or a shift from punishment to positive reinforcement does not alter behavior modification’s abusive nature, which they considered fundamental:

> *Breaking down another person’s boundaries and coercing them into acting how you want them to is still abuse whether done with high fives or spankings. (TT48)*

> *If you REALLY want to help autistic people you have to admit that abuse is still happening in the name of ABA. (TT52)*

Long-term harm. Similarly, several creators discussed ABA as a traumatic experience. It was common for videos to include a trigger warning for discussion of ABA. Multiple creators talked about PTSD as a possible long-term consequence of ABA, and one creator cited Kupferstein’s (2018) study to support their assertion that ABA increases PTSD risk. In responding to another user’s question about the pros and cons of ABA, a creator replied, “The cons include life-long trauma” (TT24). Another creator, responding to a behavior analyst, referred to her personal trauma from ABA: “In your standards, I am a success story, but yet my life is reeled with trauma because of the tactics that they used” (TT19).

Creators also mentioned specific ways that ABA might be harmful to an autistic child, both in the short-term and in the long-term. Several mentioned that forced compliance could teach a child that they were not allowed to have boundaries; the first quotation appeared as on-screen text and is reproduced here exactly as written:

> *by slowly introduce touching, then reward me if I didn't react*
> *I didnt learn to be comfortable with it*
> *I slowly learned not to react (TT30)*

> *Manipulation and coercion literally teaches kids that they're never allowed to have boundaries, especially if the thing that you are punishing them for is saying no. Or not doing a thing that you've demanded. No. No. You don't get to damage your children's capability to set boundaries. And tell anybody that that's therapeutic or acceptable. (TT46)*

A few creators explicitly linked this to children becoming more susceptible to abuse. Two referred to it as grooming. One creator wrote, "And we need to consider the long-term ramifications of compliance training, for instance autistic adults being at extreme risk of domestic violence and sexual assault" (FB4).

One creator described how their personal childhood experiences with ABA cause them to have a panicked reaction when they witness their own autistic child "acting autistic":

> *I'll never be able to explain how guilty I feel for feeling panicked when I see my daughter erratically stimming and something in me goes to stop her. I don't actually do it. But I do become so nervous watching the big stim moments that I have to fight the urge to ask her to stop. It's fear, it's shame, it's the conditioning and training I was put through. I get scared for her. "They're going to see you!! Stop!!!" is what I feel/think in these moments. Who is they? The therapists? My family? I don't want to shame her into not being herself like I was. (TT15)*

Two other creators discussed how they felt their personal experiences with ABA prevented them from developing intrinsic motivation. One explained the difficulties in becoming self-motivated after learning to take direction from others:

> *I was just so used to…schedules and, um…therapies, and being on time, and doing this, and being perfect. And following direction. I didn't know what to do. If I wasn't being given direction, I didn't know what to do, and even today, I still don't know—I'm barely learning, at 26…on how to give myself direction on my own ... because ABA programmed me to think that I had to take commands from someone else. (TT56)*

Anti-neurodiversity. Some creators focused on the harms caused by ABA due to its opposition to the concept of neurodiversity. Creators talked about ABA as a tool to enforce allistic social norms and behaviors and to eliminate characteristically autistic traits, even harmless ones, in autistic children. Many creators expressed the view that ABA trains autistic children to be neurotypical; they discussed the potential harms of this, framed within the perspective that autism is a fundamental part of who autistic people are and cannot be separated from them. As one creator stated, “Our brains are wired this way, you can’t train autism out of me” (TT28). Another explained it this way:

> *Because autism is an integral part to who autistic people are … In its essential form, ABA teaches autistics to act neurotypical, to perform neurotypicality. But performing neurotypicality is not the same thing as being neurotypical. (TT7)*

Several creators directly endorsed the opinion that ABA teaches autistic children to mask[4] their autism. One posed the question, “have they improved or have they been forced into masking their autistic traits for your own comfort?” (TT21). Creators also discussed the potential negative consequences of masking, such as one who said, “Autistics have a high suicide rate, and research is pointing to masking, or performing neurotypicality, as one of the largest risk indicators” (TT7).

One creator, who did not speak in the video, used a clip from the song “Little Dark Age” by MGMT as their audio. On-screen text read, “to all the ‘autism moms’ that think they can change their autistic child using things like ABA therapy,” immediately followed by a lyric that conveyed their message: “Just know that if you hide, it doesn’t go away” (TT36). Another creator stated, “at the end of the day, masking does not change your neurology. The person will still be autistic, and masking is just gonna add more stress to that person” (TT60). One creator

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[4] Autistic people often use the word *masking* to refer to an autistic person’s suppression of their natural autistic traits/behaviors, consciously or unconsciously, in order to conform to a neurotypical world (Pearson & Rose, 2021). The literature sometimes uses the term *camouflaging* to describe this (Cook et al., 2021).

addressed her video to parents who choose ABA for their children and told them, “You’re the parent who would’ve sent their kid to gay conversion therapy camp” (TT50).

Others stressed that behavior-focused interventions might cause autistic people to suppress their needs, regardless of how painful that could be. Two different creators discussed this idea in somewhat different ways:

> *… they’re trying to train out natural behaviors in autistic children. And really what this causes them to do is camouflage and internalize how they really feel, which causes immense psychological pain. (TT28)*
>
> *Yeah, they're gonna start burying their fucking emotional needs. What they're basically being taught is, like, your emotional needs don't matter, so long as you don't act autistic, ya little freak. (TT5)*

Several of the creators used the word “pathologize” to describe how autism is treated within ABA and by its proponents. This framed ABA in opposition to the neurodiversity paradigm: accepting the medical model of disability, treating autism as a disease, and supporting the goal of curing autism. A creator explained that ABA “pathologizes autistic behavior. Pathologizes means to make, like it’s a sickness, which — autism isn’t” (TT28). Another creator rejected the notion of a “cure” for autism outright:

> *Autism cannot be cured. Autism should not be cured. Because autism is an integral part to who autistic people are. I don’t have autism, I am autistic, and proudly so. … Sadly, there are so many autistic kids who are forced to undergo ABA, Applied Behavior Analysis therapy, who don’t get to be themselves. (TT7)*

Another key point that creators raised was the importance of many autistic traits to autistic people. Several creators discussed ABA as a method used to force children to abandon useful or beneficial behaviors, or to adopt behaviors that might be uncomfortable or painful to them, to conform to a socially acceptable standard. As one creator put it,

> *And you may think eye contact or looking at you or not stimming or not watching the same video over and over again or not listening to the same song over and over again—you may think that those things are not important. But that is how we are formed. (TT41)*

Creators focused on behaviors that could make an autistic person appear “weird” to their neurotypical peers but are not harmful in themselves. Several of the creators discussed stimming and their impressions that ABA practitioners are inclined to eradicate it even when it causes harm to no one. One stated, “Self-stimulatory behavior is also targeted—something we have to do in order to regulate our nervous systems. … what you’re really doing is causing someone to be in immense pain, which causes trauma” (TT28).

As in the above reference to watching a video “over and over again,” creators also focused on the trait of “restrictive interests” as something that did not need to be fixed but which ABA might target. One creator spoke about an account she had heard in which an ABA practitioner discussed “interrupting” autistic children’s interests to teach them that they could enjoy other things. The creator continued,

> *I wouldn’t pull my mom’s book out of her hand and go shove her on the soccer field to show her that she might also enjoy playing soccer. Yes, autistic people have less varied interests than a lot of allistic people, but that doesn’t mean that we’re bored, or that our lives are not fulfilling. You might be bored with my interests, but I am not. So why are you holding me to your standard? (TT47)*

Another creator described her experience as child who was “obsessed” with a particular color:

> *… if I could not have the color blue, [I] would have a meltdown. So this is what they did to fix it. And I’m not joking. I would be put in a room with the other ABA kids, and everybody would get a blue piece of paper. Except me. And that happened for three weeks until I stopped crying. ABA is awful therapy. (TT39)*

Creators also discussed situations that could cause a child to become overwhelmed or distressed and potentially lead to behaviors that are unsafe for the child or for others. Such situations were sometimes contrasted with the harmless behaviors targeted by ABA.

Failure to address root causes of behavior. When discussing how to address unsafe behaviors, or autistic meltdowns generally, several creators expressed that use of ABA is still harmful. Some stated that ABA focuses only on observable behaviors and generally fails to identify or address the root cause. Creators discussed how this could result in a child suppressing an undesired behavior while remaining in distress. One creator explained that behavior modification was not the same as resolving stress:

> *A child who is aggressive and self injurious isn't that way by design. It's not even part of the diagnostic criteria to be autistic. Something is distressing enough that pain is actually a relief. Changing the behavior does nothing for that distress. Me not running around stores anymore literally doesn't mean stores are no longer stressful. (FB2)*

Another creator said, “And what’s really ironic to me is, behavior modification never asks why this is happening, so we’re just focused on the behavior, right?” (TT46). Discussing a technique in which a child’s behavior is ignored after being deemed attention-seeking, a creator explained, “Um, I don’t think it gets at the underlying needs, you know? It just says something’s attention-seeking but doesn’t think about why we need that attention” (TT29).

One creator talked about ABA as anti-neurodiversity and then connected that stance to ABA’s failure to address the root causes of autistic children’s distress. They summed it up this way: “We are fully formed, whole human beings. We do not need social training to assimilate to your social hierarchy. We need accommodations, we need support, and we need acceptance” (TT41).

4.3.2 Opposition to ABA as a field of practice

Many creators went beyond discussing the harms caused by ABA and criticized ABA as a field of practice, as a science, and as a profession. These criticisms were related to the history of ABA's development, potentially harmful methods that are part of standard practice, and fundamental problems at the core of ABA. Several creators also opposed the field because of their feelings that ABA is not intended to benefit the autistic person.

One creator discussed frustration about the minimal requirements for some ABA staff. Specifically referencing a job posting for a behavior technician position, they said,

> *Pays sixteen to twenty dollars an hour, and the only requirements are that you have to have a high school diploma, you have to have a reliable form of transportation, uh, you have to be available three to four times a week for four to six hours per shift…and…you also have to enjoy and be able to work with kids. And that's the only requirements. ... in-house training and blah blah blah blah. And they [air-quotes] "certify" you to be an ABA therapist and all that, or, um, ABA [air-quotes] "behavior technician." And I just think this is fucking ridiculous. (TT11)*

A few creators addressed their frustration that ABA dominates the "autism services industry" and discussed the need for alternatives. Some mentioned specific alternatives that they think are preferable to ABA. One creator wrote, "RDI over ABA!!" (TT26), referring to "Relationship Development Intervention" programs as a better alternative. Another creator held up a book called *The Dialectical Behavior Therapy Skills Workbook* and explained, "I find a good alternative to ABA is dialectical behavioral therapy … because dialectical behavioral therapy is about handling those meltdowns, while we're having them. Not about just pretending they don't exist" (TT54).

ABA's disturbing history. Several creators also expressed their opposition to ABA as a field of practice based on their knowledge and understanding of its history and past practices. A few creators mentioned Lovaas by name, usually referring to him as the founder or creator of ABA, and some read aloud excerpts from his interviews. The creators who quoted Lovaas tended to allow the quotations to speak for themselves and did not add much. For instance, one creator made it clear that he had not personally experienced ABA and asked to hear from autistic people who had, but also presented the following quotation from Lovaas:

> *"… You have the raw materials, but you have to build the person."*
> *That is the founder of ABA. That is his viewpoint, that is what he believes. (TT60)*

Another creator quoted from the same interview, in which Lovaas described using electric shock to "cure self-destructive behavior" in autistic children (Chance, 1974, p. 80):

> *He then has the audacity to go on like this… "We know the shock's painful. We have tried it on ourselves, and we know that they hurt. But it is stressful for the person who does the shocking, too. You may have used shock successfully with a hundred kids, but you are still apprehensive about it. You always think that maybe this kid will be the exception. Maybe you will hurt him, and it won't do any good. But then, when you shock him, and you see the self-destructive behavior stop, it is tremendously rewarding." (TT9)*

Like several creators, this one connected ABA's history to the present by including Lovaas's quote about electric shock in a video advocating against the JRC's present-day use of electric shock. The creator commented on the similarities between "old ABA" and "new ABA."

Several creators also referenced Lovaas's connection to the development of conversion therapy designed to change a person's sexual orientation or gender identity. One creator directly compared ABA to this type of conversion therapy:

> *[Lovass] also helped create conversion therapy as we know it today. Similar to conversion therapy, ABA tries to take something that is natural to a person and, quote, [air-quote] 'train it out of them' to make them act, quote, 'normal.' (TT28)*

This idea of ABA as conversion therapy is strongly connected to the idea of ABA as anti-neurodiversity mentioned in the previous section, especially the idea that ABA promotes masking/camouflaging. While some creators mentioned ABA's historical link to conversion therapy via Lovaas, others spoke of ABA as a form of conversion therapy without reference to this connection. Those mentions were based solely on the creators' perceptions of ABA as a way to force autistic children to act like neurotypical children.

Unacceptable methods. Many creators made references to methods that they believed to be standard practices within ABA. These criticisms were not focused on a specific agency or practitioner who might be causing harm; they were condemnations of what the creators saw as widespread practices within the field.

Some of these criticisms were of very specific practices. For instance, one creator's video focused entirely on explaining the tactic of "planned ignoring." She wrote, "Most Parents of @ut;$t:c[5] Children who partake in this practice are doing so as per instruction of ABA Therapists who have told them this is the best and only way to help their @ut;$t:c child." The user described the tactic as follows:

> *… when an autistic child is … expressing discontent in any way that they deem unacceptable, instead of … getting to the root cause of that issue, that behavior basically gets written off as attention-seeking, and their solution is you just ignore the child completely. Because they're a child, who depends on their parents for love and affection, the choices become, "well, I could either accept the fact that my emotional needs don't matter and just behave like a good little neurotypical, or my parents can just never acknowledge me again." (TT5)*

Creators discussed their opposition to ABA's methods in a variety of ways. Several creators used words like "coercion," "manipulation," and "forced compliance." Some creators expressed broader criticisms of behaviorism/operant conditioning in general:

> *I was taught to have good social interactions for a sticker. (TT1)*
>
> *They took away my phone because I couldn't tell a story in chronological order. (TT55)*
>
> *You do realize that withholding a reward is itself a punishment, right? (TT25)*

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[5] Due to concern that TikTok's automated content moderation will flag certain terms (Ohlheiser, 2021), or that the algorithm might suppress videos that include certain words, some creators choose to self-censor terms (in this case, "autistic").

> *I think the thing that is most troubling to me about behaviorism, is that describing relationships as a series of transactions is really dehumanizing, as is trying to describe people as a series of inputs and outputs. (TT8)*

Other creators also described ABA's methods as dehumanizing. Some directly compared it to "dog training." One creator responded to, and agreed with, a comment that read, "I remember reading an article about an actual dog trainer that said dog training is more ethical than ABA" (TT44). This idea of dehumanization was closely linked to criticisms of behaviorism, both through relating it to the use of operant conditioning to train dogs and the reduction of human interactions to a mechanical process. One creator summed up several common objections to ABA's methods:

> *The methodology of ABA is designed to dehumanize disabled people and silence any cries of objection we could possibly make as bad behavior to be extinguished. ... ABA uses euphemisms, but we've lived it. We know there's no difference between "ignoring the person" and "ignoring the behavior" when we've been the ones crying alone.* (TT48).

Core problems with the science/profession. Creators also spoke about their opinions that some of the problems with ABA are fundamental to the core of the field and cannot be fixed by reforming ABA. Some made this point by responding to pro-ABA arguments that "not all ABA is bad" and comparing this to phrases such as "not all men" or "not all cops." The implication was either that their criticisms *do* apply to all ABA or that "good ABA" is rare enough to be irrelevant to the discussion. For instance, one creator referenced the controversy over practices at the JRC by writing, "If the Judge Rotenberg center can electrocute autistic people in 2021, it may not be all ABA but it's enough ABA" (TT52). Another creator also referenced the JRC by using the hashtag "#StopTheShock," which has been used to advocate for banning the GED device used there, but they did not discuss the JRC in their video. Instead, they took the position that there is no “good ABA,” writing that “‘nice’ ABA is the kind that the majority of people online were traumatized by. … The ABA done as intended is the kind causing the most harm” (TT48).

Another video’s description read, “Even good ABA is still bad” (TT54). One creator emphasized their opposition to ABA on a fundamental level: “It literally teaches your child how to act neurotypical. I don’t care what amazing new ABA therapist you’ve found, that is still the core of ABA therapy” (TT45).

For other people’s benefit. Creators also expressed their opposition to ABA based on their view that it is designed to benefit people other than the autistic child. The “other people” most commonly referenced were the child’s parents and caregivers, but some also commented on ABA being done for the benefit of the practitioner or “neurotypical society.” One creator said that “ABA does nothing except make the adult feel better, make them think their child is what they think is normal” (TT28). Addressing parents who choose ABA for their autistic children, one creator stated, “You’re doing what’s best for you, not your child” (TT45). Another asked, “So who was ABA made for? Autistic people? [shakes head] Nah-o. Or was it for their neurotypical families and the neurotypical community?” (TT42) A different creator also posed a rhetorical question: “…is ABA for the betterment of the autistic child…or was ABA created to force autistic children to mask their autism so that they do not inconvenience non-autistic people?” (TT60). In these videos, creators expressed their perspectives that ABA is not in the best interest of the autistic child but exists for the benefit of others.

4.3.3 Need for nuance in discussions of ABA

In the Facebook posts, the theme of “need for nuance” emerged clearly. Several of the TikTok videos expressed this perspective as well. One TikTok creator responded to their own older video and explained why they no longer held the views expressed in it (the older video was subsequently excluded from this analysis and replaced by the new one, to better reflect the creator's perspective):

> *So in that video, I'm kind of using a sound to kind of poke fun at autism moms and at people who put their children in ABA, saying that ABA is abuse. Unfortunately, the lack of nuance that I communicated in that video is actually harmful. Because yes, ABA is abuse. But there's more to it than just that. (TT64)*

ABA is a leaf, not a root. Creators talked about ABA as being symptomatic of larger systemic problems, rather than being the problem in and of itself. These creators spoke about systems of oppression in the U.S. that result in interventions such as ABA, and they raised the issue of ABA's place within the structure of white supremacy and capitalism. Advocating for more nuance in discussions of ABA, a creator talked about how the systems that exist in the U.S. can result in ABA being a family's only option:

> *And because this country is run by a bunch of white supremacist, fascist scumbags, we don't have a whole other — lot of other options available. ... We do need a full disability support system in America, but we don't have that .... So sometimes ABA is necessary.* (TT64)

In the first Facebook post analyzed, the creator expressed her frustration with feeling compelled to speak about ABA because of pressure from the autistic community. She emphasized that white autistic people's priorities were different from her own; as a Black autistic mother of Black autistic children, addressing ABA had never been among her priorities. She wrote, "I never wanted to focus on ABA because that has always been a leaf to me. And I am all about roots" (FB1). She wrote that spending time to discuss ABA was "taking away from the very real work I feel that we should be focusing on, and that is dismantling the systems that birth ABA in the first place" (FB1). She wrote at length about ABA as a symptom of larger problems:

> *ABA is not the problem. It is a symptom. Of a society that is compliant based and hellbent on maintaining a hierarchy of bodies it deems worthy and unworthy. … I am explaining*

> *… how we are not focused on the right things, and that eradicating something that has served as a tool of safety and survival for generations, regardless of what you want to call it, and not addressing why it's needed in the first place solves jack shit ... ABA is systemic, woven into every fabric of society because it is born of a society that demands compliance. But not just compliance of all people. Just…certain bodies. Of certain status. Of certain worth. ... the ableism they face isn't something that just materialized, but is a mechanism of racism. And will always be a mechanism of racism, always existing, and as long as racism does, so will ableism. ... ABA is systemic, a symptom, and of a racist, capitalist society. (FB1)*

The other Facebook posts offered similar sentiments. One creator expressed the idea that just getting rid of ABA would not solve the problems of many families. They wrote, "It's so very therapeutic to tear things down. But we must build something in it's [*sic*] place. 'ABA is Abuse' is true. But it is not enough for me anymore. We don't all have the privilege" (FB2). Another creator noted that "People with race and class privilege are more likely to have access to care and support. While people without it are more likely to be subject to brutality and carceral institutions" (FB3).

Several creators discussed ABA as a survival tool for some families. One mentioned the choice that they imagined some parents might have to make: "You either put your kid in ABA, or the cops are gonna murder your child. You either put your kid in ABA, or your kid's gonna hurt themselves. Or someone else" (TT64). Another wrote about her own experience as a Black woman trying to navigate systems for survival:

> *... you are focusing your efforts on removing the strongest means by which Black bodies survive in this society, behaviorism, which will leave us more vulnerable than we already are, and are doing jack shit about the systems that keep us at a disadvantage, harm us, and birthed ABA in the first place. … this is about the subjugation of our person and how every single day, for generation after generation, we have taught ourselves and each other how to survive the dangers and violence of these systems. Regardless of disability. ... It should not be normal. But for so many of us, it kept us safe. ... So, when we have children, we have to teach them what was taught to us. Because that is how it is. Because that is how we make it. That is how we survive. (FB1)*

Another creator explained,

> *Behavior modification does not solve systemic racism, ableism, and brutality. But people cannot wait until these problems are solved, when they are facing them now. They have to do what they have to do to get by. ... For the most marginalized people, masking is not about trying to fit into a racist and ableist world. It is about surviving this racist and ableist world. (FB3)*

This creator's last point contrasts BIPOC autistic people's experiences with masking to the way that many white autistic people discuss masking. They speak about the pain and distress of hiding their autistic traits to be more socially acceptable to those around them and to better fit in with neurotypical society. This creator noted that, in comparison, "Black and brown people modify their behavior to survive racist and anti-Black systems" (FB3). She discussed survival in the most literal sense; she addressed not only economic survival (e.g., obtaining and retaining employment) but also immediate physical survival as contingent upon appearing as non-threatening as possible. She compared this type of masking to the way that Black people and other people of color, whether autistic or not, engage in code-switching and/or assimilation, which also requires suppressing their genuine selves and can also be necessary for survival. The creator acknowledged the harm that masking can cause but emphasized the harm that *not* masking can cause to BIPOC autistic people: "Masking and not masking both kill" (FB3). Describing a similar perspective, another creator said,

> *ABA is so much like Black parenting that of course we have a hard time seeing it as abuse. I watched a video where a woman was explaining that ... a person should just be allowed to stim because it's harmless, you know? But this was a white woman saying that stimming was harmless. ... [For my son] stimming might not be harmless. And masking is something, again, that Black people teach their children, um, not even directly but just by living, all the time. We have our bank voice, we have our interview voice, we have our going-to-the-hospital voice, we have our amongst-our-family voice, we have amongst-our-lovers voice, amongst our girlfriends, like…there's a different face for every situation. Every situation. Masking is a part of Black culture. Codeswitching. (TT65)*

The role of race and the influence of white supremacy were mentioned frequently in the videos and posts about the need for nuance. One creator acted out a scene in their video and included the following text: “Me explaining how the goal of ABA (and other “therapies” rooted in Behaviorism) is to uphold whiteness” (TT62). Another wrote,

> *I am not just Autistic. I am Black. And I am Black, FIRST. And to much of society, I am Black, ONLY. With skin I can’t scrub, can’t hide, can’t tuck away, can’t mask…I can’t pretend to be something else. ... We have to navigate these violent systems, live lives by the might of whiteness, protect ourselves from whiteness, while also acclimating to whiteness. How do y’all think we do that? By modulating, regulating, and modifying our behavior. How do y’all think that makes us feel? Like shit. (FB1)*

This concept, that the experiences of autistic people can be very different depending on their race, was at the core of many of the messages about nuance. Multiple creators also referred to the possibility of child welfare systems becoming involved due to a child’s behavior and expressed that this possibility can be very threatening for Black families and other families of color. One added, “And pushing disabled BIPOC children into out-of-home foster care placement is life-threatening and leads to the worst possible outcomes” (FB4).

Mixed feelings about ABA. Several creators expressed mixed feelings about ABA, largely informed by personal and professional experiences. One commented that he had received ABA as a child but only at a young age; though he could not remember his experience, he explained that his mother said it was helpful. After mentioning another autistic creator who strongly opposes ABA, he offered the following opinion: “For now, my thoughts are that it either depends on the ABA therapist, or who the child is, or the day that it’s being done on” (TT51). Another user, who talked about having been in a long-term ABA program, tried to hold back tears while describing their feelings about ABA:

> *I have very mixed feelings on my ABA experience. ... There were things that happened to me that weren’t right, but it’s so hard because I don’t think I’d be here without ABA. ... I wouldn’t be doing what I am right now if I didn’t learn all these tactics that ABA taught. ... ‘Cause when I did try to unlearn them, it tore me apart. I had to drop outta high school ... And it’s not like I’m like, “yo, go ABA,” that’s what people assume when I say that. But it’s just ‘cause, I wouldn’t be here, it’s a factual statement, okay? And like, the worst part about it, and the hardest part, is that, although ABA is an abusive practice, the*

> *people at the program loved me. … Like how am I supposed to hate the people that were trying to be genuinely helpful and cared about me and my family? … I would never wish it on anyone else, nor would I put my own children through it, but God, it was my only option. (TT14)*

This creator was the only one who spoke about personal experiences with ABA with ambivalence. They expressed difficulty sharing this nuance with other autistic people online because other autistic people typically became angry with them.

Benefits of ABA. Most creators who discussed the benefits of ABA talked about them within broader systems of harm, as discussed above; for them, ABA was not positive in itself but a necessary tool of survival and the "least bad" option. Only one video, created by an autistic adult who stated that they were also an RBT, was entirely uncritical of ABA. This creator explained, "The point of ABA therapy is to eventually wean off of ABA therapy, is to have less therapy. We want them to be independent and have functional lives as adults" (TT40). Other creators mentioned some potential benefits of ABA as well, but they did so within the context of larger criticisms. One noted that "once you get past all the weird ableist 'pretending to be a neurotypical' stuff, the rest is just… good life skills" (TT49).

Parents are not the enemy. Another subtheme was the need for nuance in ABA discussions because allistic parents of autistic children are not the enemy of autistic adults. (Many creators expressed a sentiment of friction between these two groups, discussed in greater detail under the "conflict" theme.) Several creators encouraged nuanced discussions of ABA because of a desire to improve communication with allistic parents. They advocated for compassion and support for parents who might be struggling and doing what they believe is best for their children. One creator expressed opposition to ABA but also said, "My criticism is not of parents put in an impossible position by a society that doesn't value child-rearing" (TT6).

Another wrote that "it's not my place to speak on something that someone is doing to ensure the safety of their child/children" (TT12).

In their video description, a creator wrote, "if our goal is to get kids out of #aba we need to stop shaming #autismmoms and start offering support tools"; in the video, they also said that "yelling at parents with limited resources … just drives them back into the arms of the oppressors" (64). In this case, the creator supported autistic self-advocates' goal of "getting kids out of ABA" but focused on finding better ways to achieve it.

Other creators discussed the importance of parents/caregivers to an autistic child and the way that the child's well-being is fundamentally linked to the well-being of the parent. One person wrote, "I can't support disabled kids and not the people who care for them" (FB2), and another expressed the same idea while stressing the importance of parents' mental health to children's well-being:

> *And we need to protect the mental health of autistic children and parents - because parent mental health is a foundation of healthy and safe parenting. ... And we need to educate people and meet them where they're at. ... And if parents and primary caregivers are not supported, they can't meet the needs of their autistic children. (FB4)*

Some creators also made clear that being supportive of parents was particularly important for Black parents and other parents of color; low-income parents; and parents whose autistic children had more concerning and unsafe behaviors. One creator explained,

> *ABA is based on a racist colonizing system just like the legal system ... The racist conniving nature of ABA is why I'm asking y'all to have compassion for families and black families in particular ... The choice is "abuse" or "abuse" for many of these families. (FB2)*

Several creators also mentioned the need for discussion about how to make ABA less damaging for autistic children, such as by making videos to help parents evaluate ABA programs and educating them about "red flags" that might indicate an especially bad program. Some used the term “harm reduction” to describe this idea: “when [ABA is] necessary, we need to give parents and teachers the tools to do it in a harm reductionist way” (TT64).

4.3.4 Conflict in discussions of ABA

Many creators illustrated or discussed various types of conflict that they had experienced or witnessed while talking about ABA in online and offline spaces. Much of this conflict set two different groups against each other. Creators described conflict between allistic ABA supporters and autistic adults, and some demonstrated this conflict because their videos were direct replies to comments or videos from ABA supporters. Creators expressed feeling frustrated and as though ABA supporters did not accept or value their opinions.

The videos and posts also discussed and demonstrated conflict within the autistic community. This was strongly connected to the “need for nuance” theme, as conflict tended to arise between creators who advocated for more nuanced discussions and those who maintained an uncompromising stance against ABA.

ABA practitioners vs. autistic adults. Many creators positioned themselves, as autistic adults, in opposition to ABA practitioners, and they also tended to describe ABA practitioners as threats to autistic children. One creator wrote, “ABA therapists who are in denial are literally very dangerous to the autistic community” (TT10).

In several videos, the creator responded directly to a video or comment by an ABA practitioner (often a BCBA) using one of TikTok’s features or a screen recording. In one case, the creator responded to a BCBA’s video that explained ABA; in addition to responding with a criticism of ABA, the creator wrote in the video description, “I don’t need to tell you what I’ll do if you (and your fellow child abusers get that shit anywhere near my autistic child.)” (TT17).

This quotation is presented exactly as written, though the creator likely intended to include only the phrase “and your fellow child abusers” within the parentheses.

A different creator referred to the frequent conflict that happens in the comment section of any anti-ABA social media post. She yelled, “I don’t care what ABA therapists come up in my comments going, ‘Oh, but it’s different, oh but you really don’t understand what it is.’ I don’t care! ABA therapy is abuse! … Like, just say you hate autistic people and move on” (TT23). Similarly, another creator acted out a quick scene using a TikTok audio clip and on-screen text; after a line in which they criticized ABA, the on-screen text read, “BCBAs, RBTs, and other bootlickers coming to defend their abusive practices” (TT62).

Within the videos and posts analyzed, clear-cut distinctions were not necessarily made between conflict with ABA practitioners and conflict with “autism moms.” Many creators referred to “ABA supporters” generally, and many seemed to consider pro-ABA professionals and pro-ABA parents to be part of the same group, positioned against autistic adults.

“Autism moms” vs. autistic adults. Despite that overlap, just as some creators specifically addressed conflict with practitioners, others specifically addressed conflict with parents. Two separate creators (TT21, TT34) used the same audio clip to present a dialogue between parents and autistic adults. The audio was from the song “All Eyes on Me” by Bo Burnham, and the clip included the lyrics “You say the ocean’s rising / Like I give a shit.” In both videos, one side of the dialogue is connected to each lyrical line to illustrate the conflict between autistic adults and allistic parents of autistic children. In one of the videos, the on-screen text first reads, “Autistics trying to explain how traumatic ABA is” (“You say the ocean’s rising”), and then reads, “NT parents of autistics / ‘but it helps my child!’” (“Like I give a shit”) (TT34).

Another creator’s video directly responded to a parent with whom they had been arguing in the comment section of another video. In the comment to which they responded, the parent told the creator that it was “obvious” that they had “healing to do,” adding, “Not everyone’s experience is yours!” The creator responded, “Hello, [air-quotes] ‘autism mom’. My healing journey is none of your business. … I have advocating work to do. … And none of this is your experience. This is your autistic child’s experience. Do better” (TT41). Other creators expressed a similar idea, that allistic parents of autistic children too often conflated their own experiences with their children’s.

Some creators criticized parents directly and explicitly. One said, “I know it’s afternoon, but I woke up and chose violence today. … If you are the parent of an autistic child, and you put them through ABA, you’re the worst kind. … You’re destroying your kid” (TT50).

Autistic people are the experts. Central to this conflict between autistic adults and allistic ABA supporters are the questions of “whose opinions matter?” and “who are the experts here?” The videos that addressed this conflict often answered both questions with “autistic people,” and they tended to express frustration and anger about ABA supporters disagreeing with that answer.

Many creators asserted that ABA supporters often invalidated either them personally or autistic adults generally. This included being told they were not “really” autistic or that the current presentation of their autism meant that they could not understand autistic children who had different needs. It also included being told that they did not have the requisite educational background to have valuable opinions, or that their opinions were not based on anything of substance. For instance, one creator consolidated some of the comments she had received on anti-ABA videos and used on-screen text to show them. The on-screen text read, in part, “You don’t agree with ABA? That’s because of what you read on Twitter, right? … Do you actually know anything about the special education system, people with high needs including self-injurious Behavior, or ABA?" (TT4). The user then showed the covers of several books that she had read on those topics. Another video that presented a dialogue between a hypothetical ABA supporter and the creator showed the ABA supporter saying, "You just don't understand the science" and the creator responding, "No, I do. Better than you, actually" (TT25).

Other creators talked about their lived experiences, either of having received ABA or of being autistic, and the value that those lived experiences should be granted. One creator responded to a BCBA as part of an ongoing argument, expressing anger and frustration at being invalidated:

> *We are talking about autistic people and the trauma they have developed from ABA. [leans in, points to self, whispers:] Like hey, I'm one of those people because I actually went through it, because I'm autistic and you're not. [cut to slightly wider shot, back to regular tone:] You have made me angry because you can't even bother to listen. You continue to ignore anyone that's even remotely disabled, like a coward. You are a coward. (TT19)*

Several other creators expressed similar frustration that ABA supporters were unwilling to listen to them, and one connected this to bad practices as an ABA professional. As part of a "dialogue with self" video, the creator told an "ABA practitioner" character, "I find it really hard to believe that your Autistic students are being heard and having their opinions taken seriously considering that you're literally talking over Autistic people right now" (TT25).

Many creators expressed that autistic people should be seen as the experts on autism and therefore, as the experts on ABA as well. They emphasized the importance of their own lived experience. One creator simply wrote, in their video description, "Please listen to autistic people" (TT52). Another discussed ABA, masking, and suicide risk, before asking, "Autistic voices have been saying this for years. Have you been listening?" (TT7).

Creators spoke about the need to position autistic people as experts on the topic, rather than practitioners and researchers who may have no idea what their experiences are like. One creator said, “The field of psychology treats ABA therapists as if they’re experts on autism, but in reality they only know enough about autism to punish observably autistic behaviors” (TT24).

Conflict among the autistic community. Many videos and posts also referenced or illustrated conflict between members of the autistic community. Some were between two individuals, but many others did not address anyone personally. These conflicts were between sub-groups of the community that represented different opinions on a topic.

ABA-related conflict often involved debate about the need for nuance in discussions of ABA. The differences of opinion on this topic often reflected the differences in autistic people’s experiences. Creators who had personally experienced ABA often had very personal reasons for wanting to discuss ABA in specific ways. For instance, one creator who had experienced ABA as a child talked about how sharing those experiences caused them to relive their trauma. They noted that this was especially painful when the response from an ABA supporter was invalidation. They explained why they used the phrase “ABA is abuse” instead of going into greater detail:

> *… people keep telling us that we can’t say “ABA is abuse” because of how they perceive the way we said it. … it has been put on the abused to be responsible to retraumatize ourselves. When we say “ABA is abuse” — it’s simple. We’re putting a feeler out there. That’s it. We’re trying to feel if someone’s going to just discredit us completely. ‘Cause when we put a full paragraph of exactly what happened to us, and we get met with, “Not everybody has the same experience,” that is terrible. … that is why you see just that short answer. It is a conversation-starter. … We’re exhausted. This has been going on for decades. Not just when social media became big. Decades. Of us saying, “Hey we don’t like that, please stop, it’s abuse.” Decades. Of telling our stories. (TT32)*

The creator also said that autistic people who had not experienced abuse from ABA should not tell others how to talk about it, “And just because you’re autistic, doesn’t mean you get to speak on ‘ABA is abuse.’ Leave that to the ones that are abused. You don’t get to decide how we respond to this” (TT32). On the other hand, a creator who had personally experienced ABA felt that they were unable to ever express their mixed feelings about it due to the prevailing anti-ABA sentiment in the autistic community. In a video about their experience, they said that they were going to “make a lot of people upset” before discussing how ABA had helped them. They explained that they did not feel like they could talk about this without others reacting in anger: “…when I say that ABA is … why I’m here, ah, people get so angry” (TT14).

As discussed earlier, the “need for nuance” theme often hinged on the ways in which systems of oppression, especially white supremacy, shape the experiences of Black autistic people and other autistic people of color. Disagreements due to different perspectives, especially due to race, were also a common type of conflict among the community.

Self-advocates who supported nuance and those who opposed nuance typically all agreed with the basic idea of ABA being “bad” (or at least mostly “bad”). Their conflict was about the best ways to advocate against ABA, how to approach ABA-related conversations, and whether ABA was even worthy of being a priority. One creator addressed the anti-nuance group by highlighting the advocacy work done by pro-nuance self-advocates and also highlighting the need to “include multiple identities” when doing advocacy work:

> *We need y’all to live on planet earth with us, in reality. ... The very same people y’all yell [“abuse”] at are the people trying to do more than type online. Your advocacy isn’t less, but it’s not better. You have every right to anger. We need it, like I said. However, I’m going to use it and advocate MY way, which includes multiple identities, and I will continue to encourage others to do the same. (FB2)*

The conflict described in the Facebook posts, especially, is not only about ABA but about the larger issue of white autistic voices being centered within the community: “I looked at my boys and I am tired of what is considered ‘advocacy’ speaking for my children. For all of your children, honestly. And for my damn self" (FB1). This creator expressed her concern, too, that even as conversations about ABA become more nuanced, the focus has remained narrow. She wrote that harm done to Black autistic people and others comes from every part of society, so focusing only on improving ABA or funding alternatives does not actually address that harm:

> *It appears many are now focusing on harm reduction, alternatives, parental resources, etc. all things related to and/or surrounding the structure of ABA. This, I do not disagree with per se…however, this does absolutely nothing for those when they leave the therapy centers. We still live within a society that demands so much from us in order to survive and exist. No amount of conscious parenting, discipline, harm reduction, etc. will change that. (FB1)*

5.0 Discussion

Based on prior knowledge of anti-ABA sentiments among autistic adults in various online spaces and the limited previous research, the descriptions of harm caused by ABA and opposition to ABA as a field of practice were unsurprising. Nonetheless, many of the creators expressed specific criticisms of the field and specific ways that they felt ABA to be harmful. This provides important insight into what elements of childhood interventions autistic adults denounce, and such insight can inform practices based on what autistic adults consider valuable.

The conflict between autistic adults and allistic ABA supporters was also unsurprising. These interactions indicate a need to acknowledge and promote autistic adults as autism experts and grant value to lived experience. The descriptions of these conflicts reveal that, despite increased recognition of self-advocacy and research inclusion in recent years, autistic adults continue to experience invalidation when they express their experience-informed perspectives. Elevation of autistic voices on autism-related topics is crucial.

A particularly salient finding in this study was the layer of conflict among the autistic community around the subject of nuance in conversations about ABA. Black autistic parents of Black autistic children emphasized that ABA is often a tool for surviving within systems that could tear apart their families. They expressed that “banning” ABA would not actually help families like theirs but *would* take away one of the few survival tools that are available to them. They communicated that, like the white autistic adults who merely state that “ABA is abuse,” they generally agree that ABA is about training children to suppress their autism, and this is harmful and damaging. However, these creators further explained that, for Black autistic children and other autistic children of color, this suppression can be necessary for survival. More than that, they asserted that compliance with the dominant society's norms (including by masking one's genuine self) is not restricted to only autistic children. Rather, it is a tool of survival for most if not all racially minoritized people in the U.S. While ableism requires this of even white autistic children, white supremacy requires it of all people of color.

Childhood autism interventions cannot be informed only by the inclusion of white autistic perspectives because a lack of deliberate inclusion of racially minoritized autistic people is no different from deliberate exclusion. The present study highlights the way that systemic racism leads to very different experiences. This work, therefore, must be highly conscious of how existing oppressive systems impact the way that the world perceives BIPOC autistic people and how such perceptions can endanger them. This understanding is necessary to balance the sometimes-competing priorities of respecting autistic children's autonomy, ensuring the physical safety of autistic children, and working to dismantle systems that threaten both their autonomy *and* physical safety.

5.1 Harms and Invalidation

The results of this analysis show that many autistic adults oppose ABA and view it as harmful. This aligns with previous findings (McGill & Robinson, 2020). The disconnect between autistic people's perspectives on ABA and the perspectives of healthcare professionals is a reason to pause and consider why. It is easy to assume that autistic people who are capable of advocating for themselves are somehow fundamentally different from autistic children who are nonspeaking or engaging in extremely dangerous behaviors, but that ignores the fact that some of the autistic adults advocating against ABA *were* once those children. Some were completely nonspeaking until late childhood or adulthood; some still are. Some were or still are partially nonspeaking. Some were aggressive, self-injurious, or otherwise engaged in “extreme” behaviors that threatened their own safety or the safety of others. That so many people are opposed to a treatment that is meant to help them and people like them is cause for concern, even if not every single member of that population opposes it. What is particularly important is the inclusion of autistic people in the design of interventions for autistic people.

Most of the creators in this study shared the perspective that ABA is harmful, and many discussed specific aspects of ABA that they find concerning. Creators mentioned the need to look at the root causes of a child’s behavior and figure out how to help relieve the distress that the child feels, rather than simply modifying the child’s behavior so that they stop expressing their distress in ways that are deemed unacceptable. They named compliance as a poor objective; they mentioned force, coercion, and manipulation as ways that a practitioner might gain a child’s compliance. Creators also discussed their perspectives that ABA coerces autistic people into masking their autistic traits and pretending to be neurotypical, which has been associated with negative outcomes (Cage & Troxell-Whitman, 2019; Hull et al., 2021; Pearson & Rose, 2021).

5.2 Intersectionality and the Need to Acknowledge Race

Creators made the point that the experience of Black autistic people and other racially minoritized autistic people is not and cannot be the same as that of white autistic people. Considerations of race within most autism research is restricted to a fairly narrow focus on identifying disparities in diagnosis and treatment (Durkin et al., 2017; Mandell et al., 2009; Smith et al., 2020; Zuckerman et al., 2017). However, the race-based differences in the experience of autism hardly end there. Narratives and representations that fail to acknowledge the existence of Black autistic people, for instance, not only make it more difficult to receive proper diagnosis but also make it harder for Black autistic people to exist as themselves *after* receiving a diagnosis (Matthews, 2019). The compounding effect of multiple marginalizations must be acknowledged, and intersectional theory has already paved the way for this to occur (Crenshaw, 1989).

That white autistic people ignore the needs of others within the community is not news, nor should it be particularly surprising (Giwa Onaiwu, 2020). Race and the ways in which it intersects with autistic identity must be acknowledged. For researchers, this means adopting the mindset that inclusive research *must* be intersectional (Cascio et al., 2021). Regardless of the level of involvement of autistic co-researchers, a study cannot be genuinely inclusive if it includes only white autistic people. It is important to consider other intersecting identities as well, and it is also important to recognize that some identities (e.g., white women) have been more elevated within the self-advocacy community than others.

Though the present study focused on ABA, the inclusion of additional content from autistic creators of color demonstrated that some of their priorities may be very different from those of white creators. Not only did these creators express the perspective that the conversation around ABA should change, but one was also very clear that she did not want to engage in conversations about ABA at all. It simply was not a priority for her, and she resented feeling forced into that conversation due to pressure from white self-advocates. Research agendas cannot be set inclusively with white autistic people only — researchers would simply be trading one version of exclusion for another.

5.3 The Role of Inclusion in Conflict Resolution

The theme of conflict emerged clearly from the videos and posts analyzed. This is perhaps unsurprising given that arguments are commonplace on social media platforms (Baughan et al., 2021). The conflicts identified can offer important lessons about the needs of the autistic community.

Disagreement is not in itself negative but often a necessary part of progress. Finding tools and strategies to aid in consensus-building can be especially challenging, however, when the boundaries of a group are mutable, and the conflict comes from many issues at once. Online arguments may be more productive when the relationship between individuals is centered (Baughan et al., 2021). A subtheme uncovered by this analysis was about conflict within the autistic community, most of which arose from disagreement about how to discuss ABA or even, perhaps, *whether* to discuss ABA at all. Creators had little outright support for ABA, but several expressed that ABA is only a small symptom of a much larger problem. A clear racial divide exists on this issue as well, with white autistic adults positioned in opposition to BIPOC autistic adults. However, several white creators also expressed the need for nuance in discussing ABA and used their own platforms to share the points made by Black autistic creators. They expressed having learned from Black autistic people, Indigenous autistic people, and other autistic people of color. They spoke about their opinions on the subject having evolved and urged other white autistic people to read posts by autistic people of color. All of this demonstrates a centering of relationships and willingness to listen that can lead to forward movement for an entire community, as community norms and priorities readjust.

At the root of this conflict — within the community as well as between the community and allistic people — is the question, *who are the experts?* Autism research has historically disregarded the voices of actual autistic people, and it has been only a short time since this population was even considered capable of participating. The rift between autistic people and ABA practitioners comes from a central conflict about who holds the expertise and what expertise even means. This tends to pit formal education and professional experience against lived experience. Many of the pro-ABA arguments that autistic creators refuted were intended to highlight autistic people's lack of expertise: about ABA itself, about behaviorism generally or psychology as a whole, and even about how autism works. Some creators countered these arguments by citing books and peer-reviewed journal articles or by mentioning their own academic credentials. Others simply took the stance that they are experts solely because they are autistic, and lived experience is more valuable than secondhand experience.

Conflict between autistic adults and parents of autistic children seemed to come from a similar but not identical place. It generally stemmed from what was perceived as autistic parents' refusal to listen to autistic adults about what is best for their children. Autistic adults are often working to prevent harm to autistic children. However, online parenting discussions are also extremely fraught with conflict and negative judgment, and parents of autistic children experience frequent judgement both online and offline (Ammari et al., 2014; Tathgur & Kang, 2021). As such, they might not be receptive to autistic adults' advice in online spaces. In addition, parents also might not consider autistic adults to be experts on autism, especially if their advice conflicts with the advice of doctors, psychologists, and others whom the parents *do* consider to be experts.

The conflict here arises from feeling unheard. When autistic people perceive that their opinions are ignored, while the views of parents/caregivers receive more weight, they are justifiably angry. When they are left out of consideration, and ABA practitioners and pro-ABA organizations discount and invalidate their experiences and opinions, conflict is inevitable. When Black autistic people, Indigenous autistic people, and other autistic people of color are pushed to the side in the autistic community — when their experiences and feelings and ideas are forced to take a backseat to the white autistic community’s priorities — there is still more conflict.

It may not ever be possible for everyone to fully agree, but centering autistic people in work that is about and purportedly *for* them is absolutely paramount. It is, however, not enough without intentional efforts to include autistic people with other marginalized identities. On the topic of ABA and autism interventions in general, it is important to include BIPOC autistic people in these conversations. Their needs are often different from white autistic people’s and will continue to be, at least until major progress is made toward tearing down the systems that make ABA seem necessary for their children in the first place. People within and outside of the autistic community must recognize that not all autistic people have the same needs. Autistic people with intellectual disabilities, nonspeakers, and others who need greater support must be included as well.

In recent years, research has begun a general trend toward inclusive approaches. Collaboration, or at least engagement, with communities is an increasingly popular practice in many areas of research, including autism research (Roche et al., 2021). Several teams have engaged the autistic community in projects designed to guide priorities for autism research. The level of community inclusion has ranged from researchers using qualitative methods to solicit community input (Pellicano et al., 2014) to establishing co-leadership with the community (Benevides et al., 2020). The continued use of these methods in research will not only elevate autistic voices in response to specific questions but will also help to solidify a paradigm that acknowledges autistic people as autism experts.

Research about autistic adults' needs specifically, has been the most likely to include autistic people as collaborators. In contrast, biomedical autism research has rarely been conducted inclusively with non-academic autistic partners. Most relevant to the present discussion, research about interventions for young autistic children has also seldom been done collaboratively with autistic adults. Parents, caregivers, and sometimes teachers are more likely to be included as partners in early intervention research than are autistic people themselves. The inclusion of autistic adults as co-researchers should not stop short of research about autistic children. Autistic adults were once autistic children, and their input as autism experts is enormously valuable here. It is also possible, despite the challenges, for researchers to include autistic adolescents and children in the research process. These young autistic people can be collaborators, too, not just participants in research that is about them. Many inclusive models exist, too, that can be adapted for collaboration with autistic people with intellectual disabilities, nonspeaking autistic people, and others who might traditionally be thought of as unable to act as research partners (Embregts et al., 2018; Schwartz et al., 2020; Williamson et al., 2020). Creative and flexible researchers who are committed to elevating the opinions that matter most will find ways to involve all who have a stake in the outcome. The understanding of autistic children's experiences that autistic adults and children bring to the table cannot be overvalued.

This is an important opportunity for researchers to deeply consider how to include autistic adults in this type of research and how to engage with them to the greatest extent possible. It is also crucial for researchers to include a diverse group of autistic adults and be especially mindful of recruiting autistic people of color. As more inclusion happens and more unheard voices are elevated, conflict resolution becomes more likely.

6.0 Conclusion

The prevalence of autism has increased rapidly over the past several decades and continues to rise. Unsurprisingly, interest in autism has also grown among healthcare professionals, researchers from many disciplines, and the general public. Children are often diagnosed with ASD at a young age, and emphasis has been placed on earlier identification and treatment. Behavioral interventions are very commonly recommended to parents/caregivers upon their children's diagnoses, and many professionals regard ABA-based interventions as the "gold standard" treatment. However, autistic adults have criticized ABA, and many advocate against its use. Autistic adults' perspectives have not typically been considered in the development or continued use of autism interventions, but they can offer crucial insight.

ABA approaches use rewards and punishments for behavior modification. ABA initially gained popularity with parents of autistic children in the 1970s because it gave them hope and included them in their children's treatment, rather than the blame-and-separate approach that previous autism treatment had taken. However, ABA was developed with the goal of eliminating autistic behaviors, and physical punishments were commonly used. While such punishments are now rare, many autistic self-advocates oppose ABA based on the paradigm of neurodiversity, which emerged from the autism rights movement that began in the 1990s and holds that autism is a neurological difference but not a deficit. This paradigm rejects the pathologizing of autistic characteristics, which contrasts with the historical and continued use of ABA to make autistic children appear less autistic. Little research exists about autistic adults' experiences with ABA treatment and its long-term effects, although the research that does exist suggests ABA could be associated with several negative mental health outcomes (Kupferstein, 2018; McGill & Robinson, 2020; Sandoval-Norton & Shkedy, 2019).

Autistic self-advocates have created communities in many online spaces across the internet and use these spaces for both connection and activism. The present study sought to explore autistic adults' perspectives on the use of ABA as an intervention for autistic children, and it was conducted using social media data on the topic. The data used included 63 TikTok videos and four Facebook posts from autistic adults about ABA. TikTok videos were collected five at a time and assessed for data saturation, but white autistic creators were overrepresented. One Facebook post was identified because it was shared in a TikTok video. This post and three other Facebook posts were included in the analysis because they yielded much richer data about the perspectives of BIPOC autistic adults. The data were analyzed using reflexive thematic analysis, and four major themes emerged. These were harms caused by ABA, opposition to ABA as a field of practice, need for nuance in discussions of ABA, and conflict in discussions of ABA. Several subthemes were also identified for each.

Creators' perspectives on ABA tended to be very negative. Autistic adults, over and over, referred to ABA as abuse. They spoke about potential long-term harms that autistic children might experience, and they discussed their perceptions of ABA's disregard for boundaries and consent. Creators talked about their personal experiences of trauma from ABA, and they talked about how it negatively affected their intrinsic motivation. They communicated their perspectives of ABA as anti-neurodiversity and their opinions that it compels autistic children to suppress their needs and mask their autistic traits. Additionally, they felt that behaviorism-based approaches could not truly address the root causes of distress in autistic children.

Many creators expressed opposition to ABA as a field of practice whose underlying philosophies and standard operating procedures are detrimental to autistic people. They talked about the disturbing history of ABA's development and did not think that modern ABA was far enough distanced from Lovaas. They acknowledged that many ABA proponents were involved with "gentler" versions of ABA but expressed the perspective that even "gentle" ABA could harm autistic children.

This analysis also uncovered creators' perspectives that nuanced conversations about ABA are needed. From this discussion of nuance, what emerged clearly was the idea of ABA as merely of a symptom of larger, systemic problems. The differences in experience between white autistic people and BIPOC autistic people were described as substantial. The analysis also found themes of conflict; while this was not surprising, it did include some unexpected dimensions. Conflict between autistic self-advocates and parents of autistic children or ABA practitioners has been ongoing for years, but the conflict among the autistic community, which centers around race more than it does around ABA, was perhaps less obvious. That the autistic community tends to center whiteness and white experiences is not surprising. However, the way that creators of color discussed ABA as a tool of survival within white supremacist structures — not desirable, perhaps, but necessary — adds more key insights to the conversation surrounding ABA.

6.1 Limitations

As with all studies this one has limitations. One limitation of this study was its restriction to (mostly) the TikTok platform. That means that it presents a set of perspectives that are not representative of the autistic community as a whole. The additional inclusion of several

Facebook posts helped to mitigate this slightly, but many autistic adults were not represented. Many autistic adults do not use social media at all for any number of reasons, including lack of access and lack of interest, and future research must consider this.

The specific topic of this analysis might also have limited the diversity of the sample. If anti-ABA stances are the expectation within the autistic community, autistic adults with more ABA-friendly views might refrain from sharing those opinions. Autistic self-advocates who have not spoken about ABA did not have their opinions included. For some, as one Facebook post expressed, this might be because they have different priorities and have no desire to engage in ABA-related discourse. If this is primarily influenced by other marginalized identities, as the Facebook post suggests, then exclusion of these perspectives prevents a full understanding of how autistic experiences are different for different people, especially based on race. The difficulty in locating TikTok videos about ABA from BIPOC creators indicates that this may be at least partially the case, that is, speaking about (and usually against) ABA might be more of a priority for white autistic people than for racially minoritized autistic people.

An additional limitation was completing this study without the collaboration of autistic people as co-researchers. The collection of short TikTok videos without interaction with the creators was useful and convenient for analyzing more content than might have otherwise been possible, but it was limiting as well. Including TikTok creators as collaborators, for instance, could have resulted in a richer analysis of the data. Asking creators to analyze their own videos, or videos created by others, could result in a depth of understanding that is difficult to achieve any other way. A recommendation is that further research using similar methods strongly consider engagement and collaboration with the community. Future research can benefit from taking direction from autistic collaborators about what other social media platforms or other potential sources of data should be studied.

Still, collecting and analyzing autism-related data from a social media platform such as TikTok makes contributions, even after accounting for the limitations. One benefit is the ability to “look in” on an ongoing conversation without disturbing it, as a participant-observer (or, more accurately, a lurker-observer) who can blend into the community without disrupting or changing it. The collection of TikTok videos in this way allowed for the analysis of very authentic, spontaneously generated content that is not influenced by the research process and did not place any extra burdens onto the creators.

6.2 Public Health Significance

As more and more children are identified as autistic, the question of interventions they should receive looms increasingly large. In the U.S., ABA is typically prioritized because it is considered the only evidence-based treatment for autism. It is further prioritized because its proponents have lobbied state legislatures throughout the country to support bills that require insurers to provide coverage for it (National Conference of State Legislatures, n.d.). Public health must be concerned not only with its effectiveness at decreasing signs of autism but with understanding its potential harms. Public health must also support the amplification of the voices of marginalized people who have long had little say in what happens to them or those like them. The mental health and well-being of autistic people is directly tied to how they are treated as children, and autistic adults have expertise about how to treat autistic children that cannot be found in any other way.

The findings discussed here support the need for consideration and valuing of non-ABA interventions for autism, more focused methods for addressing specific areas of concern, and ways to determine root causes of distress. Without that, it is possible to look only at the surface level.

At the same time, public health research and practice must remain committed to acknowledging the disproportionate impact of intersecting marginalizations. It is vital to continue working to dismantle the systems and structures that are truly at the very root of health inequities in all areas, including autism. Addressing racial disparities in diagnosis, access to treatment, and research participation are important, but they are far from enough. These findings emphasize the need to highlight and uplift the most marginalized voices, and they also highlight the need to advocate for better support for all families.

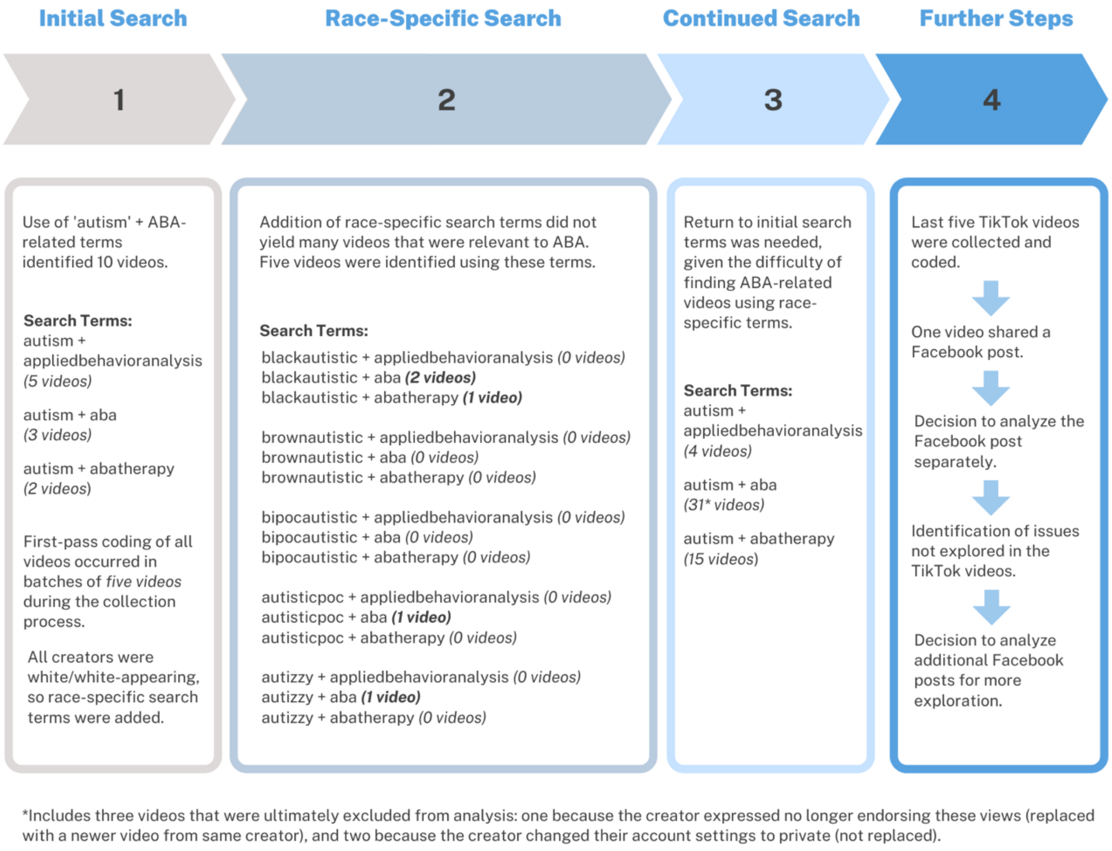
6.3 Future Directions

More study of ABA specifically is not unwarranted, but the results of this study also place ABA (as a science, as a practice, and as an industry) within a much broader context that cannot be ignored. Further exploration of the differences in experience between white autistic people and autistic people of color (especially Black autistic people and Indigenous autistic people) is highly recommended. Also recommended is specific attention to the experiences that Black families and other families of color have had with intervention/treatment for their autistic children. More general research into ABA must be mindful to include autistic people of color as participants, and all autism research must strongly consider the use of collaborative methods in order to work *with*, and in service of, autistic people.

Research that brings various collaborators together (e.g., autistic adults and allistic relatives of autistic children) to work on the development of new approaches — or the reimagination of old ones —is welcome and can potentially bridge some of the divide that exists in the conflicts discussed. The importance of forging mutually beneficial partnerships cannot be overlooked.

Families that include autistic children need and deserve adequate support to improve their lives at home, at school, and in the community. Families and caregivers deserve to be respected for their understanding and knowledge of their own children, and the lived experiences of autistic adults must also be respected as a source of vital insight into the experiences and needs of autistic children. Autistic children deserve to receive services that actually serve *them*, rather than just those around them, and such services can only do this when they are heavily informed by the priorities and experiences of autistic adults. BIPOC autistic people and their families deserve research and practice that prioritizes their experiences at the intersection of race and disability. Respect for different experiences must be freely given. Autistic children deserve services that value both their safety and their autonomy, accept them for who they are, and make the world more accessible for them. The findings presented here offer a starting point for understanding how autistic people feel about ABA. Further research that includes autistic people is essential to creating interventions and programs that reflect values and goals that are meaningful to them and not just imposed by others.

Appendix A Sampling and Data Collection Process



Initial Search

1

Use of 'autism' + ABA-related terms identified 10 videos.

Search Terms:
autism + appliedbehavioranalysis *(5 videos)*

autism + aba *(3 videos)*

autism + abatherapy *(2 videos)*

First-pass coding of all videos occurred in batches of *five videos* during the collection process.

All creators were white/white-appearing, so race-specific search terms were added.

Race-Specific Search

2

Addition of race-specific search terms did not yield many videos that were relevant to ABA. Five videos were identified using these terms.

Search Terms:
blackautistic + appliedbehavioranalysis *(0 videos)*
blackautistic + aba ***(2 videos)***
blackautistic + abatherapy ***(1 video)***

brownautistic + appliedbehavioranalysis *(0 videos)*
brownautistic + aba *(0 videos)*
brownautistic + abatherapy *(0 videos)*

bipocautistic + appliedbehavioranalysis *(0 videos)*
bipocautistic + aba *(0 videos)*
bipocautistic + abatherapy *(0 videos)*

autisticpoc + appliedbehavioranalysis *(0 videos)*
autisticpoc + aba ***(1 video)***
autisticpoc + abatherapy *(0 videos)*

autizzy + appliedbehavioranalysis *(0 videos)*
autizzy + aba ***(1 video)***
autizzy + abatherapy *(0 videos)*

Continued Search

3

Return to initial search terms was needed, given the difficulty of finding ABA-related videos using race-specific terms.

Search Terms:
autism + appliedbehavioranalysis *(4 videos)*

autism + aba *(31* videos)*

autism + abatherapy *(15 videos)*

Further Steps

4

Last five TikTok videos were collected and coded.

One video shared a Facebook post.

Decision to analyze the Facebook post separately.

Identification of issues not explored in the TikTok videos.

Decision to analyze additional Facebook posts for more exploration.

*Includes three videos that were ultimately excluded from analysis: one because the creator expressed no longer endorsing these views (replaced with a newer video from same creator), and two because the creator changed their account settings to private (not replaced).

Appendix Figure 1 Sampling and Data Collection Steps

Appendix B Characteristics of TikTok Creators and Videos

Appendix Table 1 Characteristics of TikTok Creators, by Video

Video ID	Date Posted	Creator's Pronouns	Creator's Race**	Creator's Age	Total Videos from this Creator
TT1	2021-02-01	she/her	*	*	1
TT2	2021-06-11	she/her	*	20-Something	3
TT3	2021-06-03	he/him	*	*	2
TT4	2021-07-22	she/her	*	20-Something	3
TT5	2021-06-08	she/her	*	22	1
TT6	2021-02-19	she/they	white	32	2
TT7	2021-08-29	they/he	*	24	1
TT8	2021-07-25	she/her	*	36	2
TT9	2021-07-08	they/them	*	*	1
TT10	2021-07-27	*	*	*	1
TT11	2021-08-19	they/them	Black	*	1
TT12	2021-12-26	*	indigenous	*	1
TT13	2021-02-18	he/him	Black	23	1
TT14	2022-01-12	*	*	21	3
TT15	2021-12-29	any	Black	*	2
TT16	2021-12-02	they/them	*	*	2

Appendix Table 1 (continued)

TT17	2021-12-04	she/they	white	*	3
TT18	2021-09-16	she/her	*	*	3
TT19	2020-02-17	*	*	21	3
TT20	*excluded from analysis****				
TT21	2021-07-21	she/her	*	*	3
TT22	2022-01-11	she/her	*	20-Something	3
TT23	2021-04-27	she/her	*	*	3
TT24	2021-11-19	they/them	*	*	1
TT25	2021-02-02	she/her	white	*	1
TT26	2021-09-06	he/him	*	25	1
TT27	2021-05-17	she/her	*	*	1
TT28	2021-10-11	they/them	*	23	1
TT29	2021-02-19	she/her	*	36	2
TT30	2022-01-16	*	white	*	2
TT31	2021-12-07	he/him	*	*	2
TT32	2022-01-27	*	white	*	2
TT33	2021-12-09	they/them	bipoc	*	1
TT34	2021-07-23	she/they	*	*	1
TT35	2021-11-11	she/they	*	21	3
TT36	2021-10-21	she/they	*	21	3
TT37	2022-01-15	she/her	Black	20	1
TT38	2021-09-12	she/her	*	20	1
TT39	2021-02-02	*	*	21	3

Appendix Table 1 (continued)

TT40	2021-08-13	*	*	*	1
TT41	2021-12-07	they/them	*	*	2
TT42	2022-01-18	*	*	adult	1
TT43	2021-12-19	she/they	*	*	1
TT44	2022-01-04	they/them	*	20	1
TT45	2021-11-08	she/they	*	21	3
TT46	2022-01-27	*	*	30	1
TT47	2021-12-06	she/they	*	*	2
TT48	2021-12-12	they/he/she	*	*	1
TT49	2021-03-31	they/she	white	32	2
TT50	2021-12-07	they/them	*	*	1
TT51	2021-12-16	*	*	*	1
TT52	2021-12-10	she/they	*	*	2
TT53	2021-11-23	she/her	*	*	1
TT54	2021-02-17	she/they	*	*	2
TT55	2021-04-24	she/they	*	*	1
TT56	2021-08-24	any	Black	*	2
TT57	2021-10-15	she/her	*	*	1
TT58	2021-01-18	*	*	*	1
TT59	2022-01-09	she/they	*	*	2
TT60	2022-02-10	he/him	Black	*	1
TT61			*excluded from analysis*****		
TT62	2022-02-05	she/they	white	*	3

Appendix Table 1 (continued)

TT63	*excluded from analysis*****				
TT64	2022-02-09	she/they	white	*	3
TT65	2021-11-28	*	Black	*	1
TT66	2022-01-27	she/her	white	*	1

**Missing: not provided by creator in video or profile.*
***Listed exactly as indicated (including capitalization).*
****Excluded because creator indicated no longer endorsing views expressed. Replaced with TT64.*
*****Excluded because creator changed account settings to “private” prior to analysis.*

Appendix Table 2 Characteristics of TikTok Videos

Video ID	Date Posted	Video Length (seconds)	Response to Another User?	Creator Speaks?	Location
TT1	2021-02-01	59	duet	no	home
TT2	2021-06-11	8	no	no	home
TT3	2021-06-03	15	no	no	home
TT4	2021-07-22	8	no	no	home
TT5	2021-06-08	58	reply to comment	yes	home
TT6	2021-02-19	58	no	yes	home
TT7	2021-08-29	59	no	yes	home
TT8	2021-07-25	22	no	yes	home
TT9	2021-07-08	103	no	yes	home
TT10	2021-07-27	15	no	no	home
TT11	2021-08-19	76	no	yes	home
TT12	2021-12-26	49	stitch	no	user does not appear
TT13	2021-02-18	46	no	yes	home
TT14	2022-01-12	145	reply to comment	yes	home
TT15	2021-12-29	6	no	no	Home
TT16	2021-12-02	33	duet	yes	home
TT17	2021-12-04	21	reply to screen recording	no	home
TT18	2021-09-16	6	no	no	unclear
TT19	2020-02-17	56	duet	yes	home
TT20		*excluded from analysis**			

Appendix Table 2 (continued)

TT21	2021-07-21	12	reply to comment	no	home
TT22	2022-01-11	125	no	yes	home
TT23	2021-04-27	54	reply to comment	yes	home
TT24	2021-11-19	147	reply to comment	yes	home
TT25	2021-02-02	59	no	yes	unclear
TT26	2021-09-06	17	no	no	outdoors
TT27	2021-05-17	27	no	no	home
TT28	2021-10-11	181	reply to comment	yes	home
TT29	2021-02-19	37	duet	yes	home
TT30	2022-01-16	30	reply to comment	no	home
TT31	2021-12-07	26	no	no	home
TT32	2022-01-27	180	reply to comment	yes	home
TT33	2021-12-09	8	reply to comment	no	user does not appear
TT34	2021-07-23	4	no	no	home
TT35	2021-11-11	10	no	no	home
TT36	2021-10-21	12	no	no	home
TT37	2022-01-15	7	reply to comment	no	home
TT38	2021-09-12	10	no	no	home
TT39	2021-02-02	57	no	yes	home
TT40	2021-08-13	59	duet	yes	home

Appendix Table 2 (continued)

TT41	2021-12-07	60	reply to comment	yes	unclear
TT42	2022-01-18	57	no	yes	unclear
TT43	2021-12-19	84	duet	yes	home
TT44	2022-01-04	7	reply to screenshot	no	unclear
TT45	2021-11-08	57	reply to comment	yes	outdoors
TT46	2022-01-27	180	no	yes	unclear
TT47	2021-12-06	58	no	yes	home
TT48	2021-12-12	59	no	no	home
TT49	2021-03-31	57	no	yes	home
TT50	2021-12-07	20	no	yes	home
TT51	2021-12-16	151	reply to comment	yes	home
TT52	2021-12-10	8	no	no	home
TT53	2021-11-23	110	reply to screenshot	yes	home
TT54	2021-02-17	58	no	yes	unclear
TT55	2021-04-24	58	no	yes	home
TT56	2021-08-24	180	no	yes	unclear
TT57	2021-10-15	59	reply to comment	yes	home
TT58	2021-01-18	49	no	yes	home
TT59	2022-01-09	43	no	yes	home
TT60	2022-02-10	155	reply to comment	yes	unclear
TT61	*excluded from analysis***				

Appendix Table 2 (continued)

TT62	2022-02-05	9	no	no	outdoors
TT63	*excluded from analysis***				
TT64	2022-02-09	180	no	yes	car
TT65	2021-11-28	58	no	yes	home
TT66	2022-01-27	59	no	yes	home

**Excluded because creator indicated no longer endorsing views expressed. Replaced with TT64.*

***Excluded because creator changed account settings to "private" prior to analysis.*

Appendix C Characteristics of Facebook Creators and Posts

Appendix Table 3 Characteristics of Facebook Creators and Posts

Post ID	Date Posted	Creator's Pronouns	Creator's Race*	Parent of Autistic Child(ren)	Word Count
FB1	2022-01-20	she/her	Black	yes	3,076
FB2	2021-12-31	they/them	Black	yes	834
FB3	2022-01-21	she/her	brown Asian	no	701
FB4	2022-01-06	they/them	Indigenous	yes	280

**Listed exactly as creator indicated in "About" section or within post (including capitalization).*

Appendix D Hashtags Used in TikTok Videos

Appendix Table 4 Frequency of All Hashtags Used for TikTok Videos

Hashtag	Frequency
actuallyautistic	43
aba	41
autism	33
autistiktok	20
abatherapy	16
appliedbehavioranalysis	16
autistic	14
abaisabuse	13
fyp	12
autismacceptance	12
foryou	11
autismawareness	10
asd	8
autisticadult	8
neurodivergent	5
bcba	5
autistictiktok	4
autismoftiktok	3
therapy	3
abuse	3
disabilitytiktok	3
blackautistic	3
autismmoms	3
rbt	2
caption	2
disability	2

Appendix Table 4 (continued)

ptsd	2
abatherapytrauma	2
boycottaba	2
behaviorism	2
autisticparent	2
autisticadhd	2
autizzy	2
plannedignoring	1
believesurvivors	1
parenting	1
shocktreatment	1
stoptheshock	1
ableism	1
autistictok	1
neurodiversity	1
colddays	1
xyzbca	1
autistickids	1
autismresearch	1
gnc	1
lgbt	1
psychology	1
autismmom	1
viral	1
autisticqueen	1
mentalhealth	1
mentalhealthmatters	1
autismparent	1
autistok	1
exabatherapist	1
usedandbroken	1
autistivtiktok	1
therapytiktok	1
reactingtocomments	1
differentnotless	1
autisticgirl	1
boostofhope	1

AppendixTable 4 (continued)

disabled	1
fightableism	1
autisticcreator	1
abaischildabuse	1
abakills	1
actuallyadhd	1
stimming	1
behaviortherapy	1
shock	1
stopthe	1
autismparents	1
autisticparenting	1
lifeskills	1
auntiekatie	1
behavioraltherapy	1
torture	1
abatherapist	1
aeholidayforever	1
dothejuju	1
sharethemagic	1
hdautistic	1
adhd	1
destinationdepop	1
doritosduetroulette	1
zithappens	1
earlydiagnosis	1
innerchildhealing	1
recovery	1
reprogrammingyourbrain	1
greenscreensticker	1
aac	1
autismadvocacy	1
autisticadvocate	1
nonverbalautism	1
spedteacher	1
specialeducation	1
codeswitching	1

Appendix Table 4 (continued)

masking	1
autisticwomen	1
blackautisticlivesmatter	1
disabledbipoc	1

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