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AutisTikTok: Analyzing top autism hashtags for creator, content, and persistence over time☆

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ABSTRACT

Purpose: Despite the rising popularity of the social media platform TikTok, only a handful of studies have examined the content of autism-related TikTok videos
Methods: We extracted and coded the top 40 videos from the five most popular autism hashtags at two time points (N = 400 videos; n = 275 after removal of duplicates). Variables of interest included content and creator characteristics, language use, and understandability/actionability
Results: Videos received up to 5.26B views and 9.5 M likes. Most commonly, creators were self-advocates (61.8 %) and used she/they pronouns (26.6 %). Content was most likely to use identity-first (80.8 %) and nonableist language (70.6 %) about lived experiences (75.7 %) with mixed positive and negative valence (84 %), although varied by creators. TikTok videos were understandable to lay audiences but did not contain actionable information
Conclusion: Our results suggest the media portrayal of autism on TikTok differs from the medicalized field of autism information and may serve important roles in psychoeducation and belongingness for neurodivergent communities.

TikTok, the third-most widely used social medial platform after Facebook and YouTube, stands out among its peers for its rapid growth over the last few years, particularly among individuals aged 18–29-years-old and neurodivergent users, including autistic creators and users (Auxier & Anderson, 2021; Mantas, 2024; Simpson et al., 2023). Similar to other social media, TikTok provides a platform in which individuals can share personalized experiences, engage in advocacy efforts, and build awareness (McDermott,

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2022). However, the ability for any given user to post health-related information on TikTok creates opportunity for the spread misinformation about health topics, including autism (Aragon-Guevara et al., 2023; Wang et al., 2019). Given the rapidly changing nature of social media content on platforms like TikTok (Asur et al., 2011), it is essential to examine who is producing autism-related videos and the characteristics of this content to better understand how autism is portrayed on this popular platform.

Social media and autism

Autism is diagnosed in 1 in 36 children in the United States (Maenner, 2023). The diagnosis of autism is based on the presence of persistent challenges and differences in social communication and interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that cause interference with daily functioning (American Psychiatric Association, 2013; Auxier & Anderson, 2021). Autism is more commonly diagnosed in males, with a recent childhood estimate of 3.4 males to every one female (Shaw et al., 2025). While autism has historically been diagnosed in childhood, diagnosis in adolescence and adulthood has steadily increased (Bargiela et al., 2016; Harrop et al., 2024; A.S. Russell et al., 2024; Russell et al., 2021), with many autistic adults discussing social media as a key factor in their diagnostic journey, often relating to other autistic content creators' social media (Zener, 2019).

The rapid emergence of social media in the past two decades has already had cascading effects on belongingness for autistic individuals and families with autistic youth. Autistic adults use social media primarily for social connection and entertainment purposes (Mazurek, 2013; Triantafyllopoulou et al., 2022), as well as for advocacy and recognition of an autistic cultural differences (Davidson, 2008). Consistent with themes of social connection, a study by Mazurek (2013) found that autistic adults who use social media are more likely to report having a best friend (online or in-person), with higher friendship quality among those who utilized social media for social engagement (Mazurek, 2013). Furthermore, when used in moderation, engagement with social media increased self-reported happiness and increased self-esteem for autistic adults (Triantafyllopoulou et al., 2022; Ward et al., 2018). In line with its positive role in fostering connection and belonging among autistic individuals, social media has also served as a valuable resource for caregivers of autistic youth, who report benefitting from the connection that support groups, facilitated through social media, provide (Cole et al., 2017). These findings suggest that although outcomes such as increased connection and sense of belonging may be similar for autistic social media users and their family members, their motivations for engaging with social media – and the ways in which they choose to use social media platforms – may differ.

Importantly, the neurodiversity movement, a grassroots "collective" movement (Botha et al., 2024) frequently championed in online communities, has emphasized the value of amplifying the voices and opinions of autistic individuals (Leadbitter et al., 2021), including spreading awareness and education about autism and encouraging autistic individuals to embrace and take pride in their autistic identities (Bertilsdotter Rosqvist et al., 2015). These themes of autistic empowerment and community are evidenced in numerous online communities, including blogs, YouTube, reddit, Twitter, and other social media campaigns (Mazurek, 2013; Triantafyllopoulou et al., 2022; Welch et al., 2022). For example, Welch and colleagues (2022) reported that autistic bloggers frame autism in a more positive and embodied way than the medical community, often highlighting strengths such as thoughtfulness, passion, and insight. In their work "flipping negative narratives into positive stories" (Egner, 2022, p. 1), autistic social media users consistently engage in important social activism (Egner, 2022), which has implications for how the lay community and medical community view autistic individuals.

TikTok has become a prominent platform for neurodivergent self-advocates and community members to share content and engage with others, positioning it as a potential source of both information and belonging in the autistic community (Alper et al., 2023, Aragon-Guevara et al., 2023, Gilmore et al., 2023). Emerging qualitative research suggests that creators on the platform often play important roles as neurodiversity ambassadors for building awareness, promoting advocacy, and empowering the concept of neurodiversity (McDermott, 2022). Scholars have described TikTok as functioning like a public sphere – one that not only facilitates community engagement but also celebrates neurodivergent perspectives and experiences (Berg Egge and Gabarron, 2024). This role is further underscored by community-driven efforts that influence the platform itself; TikTok served as one of the first examples of creator-driven modifications to infrastructure, as a community-organized push by TikTok creators and users urged the platform to add accessibility features (e.g. captioning) to increase access to diverse viewers (Simpson et al., 2023). Collectively, these findings suggest that TikTok may host a signification proportion of neurodivergent creators and produce a higher proportion of neurodiversity-related media, relative to other social sites.

Previous studies have examined autism-related content on TikTok, thus laying the foundation for the current study (Alper et al., 2023; Aragon-Guevara et al., 2023; Brown et al., 2024; Gilmore et al., 2023). The existing literature, summarized briefly, reported that (1) informative TikTok videos include large amounts of misinformation (Aragon-Guevara et al., 2023), (2) TikTok is a platform where people discuss their personal identities in relation to autism (Alper et al., 2023), (3) videos with over one million likes serve a primarily social connective purpose (Gilmore et al., 2023), and (4) most autism content is generated by non-autistic individuals, but is highly understandable to the public (Brown et al., 2024). To set the stage for the current investigation, it is important to consider a few methodological decisions of the latter two key studies. Gilmore et al. (2023) only reviewed videos with one million or more views under the hashtag #Autism wherein they coded for function, topic, and subject demographics (who posted the video, race, ethnicity and gender, which were scored based on viewer *perception*). Researchers noted that due to TikTok's advanced algorithms, videos with one million or more views may not accurately reflect the average users' "For You Page" and therefore findings may not be representative of the content of autism TikTok (Gilmore et al., 2023). The most recent article by Brown et al. (2024) conducted a cross-sectional analysis of 100 autism-related TikTok videos under the search query "autism spectrum disorder" to examine content type, video understandability and actionability, and whether the video was posted by a health care provider. This article used the PEMAT-A/V (Shoemaker et al., 2014), a scoring platform for online audio-visual content, to assess how understandable and actionable

(e.g., how much they generated a sense of urgency or provided resources) the content was for a lay audience. Brown et al. (2024) reported that videos classified by researchers as useful were more likely to be rated as more understandable, but less actionable. From these recent works, numerous gaps in our understanding of TikTok content remain, including evaluating what users are actually seeing on their "For You Page" (which comprise trending or popular posts not defined by number of likes), understanding who is posting content outside of healthcare providers, the type of language used by creators, and how this content changes over time.

Current study

We sought to extend the current literature to understand the relationships of content creators relative to autism, language use, video content and its understandability and actionability under common autism hashtags on TikTok. Importantly, we evaluate these metrics at two distinct time points, one month apart, to understand how trends change or remain stable over time. To extend prior research, we analyze data across two timepoints (April 4 and May 4, 2023) and under multiple hashtags related to autism (with no exclusionary criteria based on the number of likes or views). The specific aims of this study are to (1) characterize content themes, content producers, and types of videos circulated using the five most prevalent autism hashtags on TikTok, (2) evaluate the use of person- and identity-first and ableist- and non-ableist language in autism related TikTok videos, including differences in language use by content creator identities, (3) analyze change over time in content and creator characteristics over 30 days, and (4) investigate the understandability and actionability of autism TikTok content using a well-validated tool for scoring audiovisual online content, the PEMAT-A/V (Shoemaker et al., 2014).

Method

Transparency, openness & positionality

The current investigation adhered to EQUATOR Network reporting guidelines for observational studies and adheres to the STROBE reporting guidelines (Von Elm et al., 2007). Study materials, including coding manuals and raw data, are available on Open Science Framework: https://osf.io/2n6z9/?view_only=fe53f73ad09647c9b0c3e4a1f2a1037a.

The first author of this publication is a neurodivergent self-advocate and researcher. Furthermore, authors of multiple neurotypes, including two late-diagnosed ADHD authors and one autistic author, were involved in development, coding, analysis, and writing efforts. Interwoven with their self-disclosed identities, the authors of this manuscript are situated in a lab dedicated to researching neurodiversity in individuals assigned female at birth, including the interaction of assigned sex and gender. No author has any conflict of interest or vested interest in TikTok or other social media platforms, nor have they received royalties.

Video identification and export

With the goal of casting the widest net possible to capture autism content on TikTok, researchers first listed all potential autism hashtags and variants. From this lengthy list, research assistants searched each hashtag (including variant endings, such as "autisticmom", "autisticdad", "autisticson") and ranked each hashtag by number of videos using said label. This search generated more hashtags that were subsequently added to our list. The study team noted that most videos that used hashtags used 3–5 different hashtags, thus numerous hashtags generated a similar pool of Video (i.e., those who may have used "#autisticadvocate" often also used "#autistic"). At the time of the first export (April 42023 at 13:00 EST), the most used autism hashtags were #Autism (19.7B), #AutismAwareness (9.6B), #ActuallyAutistic (5.0B), #Autistic (4.7B) and #AutismAcceptance (4.0B). Videos were exported by five team members at the same time (13:00 Eastern Standard Time) to control potential differences due to the time of day the videos were downloaded. TikTok videos were downloaded on personal devices[5] on public Wi-Fi.

The first forty videos from each hashtag were exported, creating a total of 200 videos from profiles that allowed for public downloads, along with a screenshot of the video, the creator's profile, and the number of views at the time of export. TikTok's advanced algorithms tailor a user's "For You Page" based on interests, interactions, sound bites, video quality, and also content they predict may "become hot" (https://www.tiktok.com) instead of the number of views or likes a video receives; therefore, there was no exclusionary criteria regarding a video's likes, comments, and views, as in previous research (Aragon-Guevara et al., 2023; Gilmore et al., 2023). This decision to not only focus on "top" videos, but instead to capture the first forty presented to the viewer by TikTok, was made to mimic the dynamic nature of TikTok's algorithm driven "For You Page" and present an externally valid representation of what an average user may see on any given day.

The same export procedure was repeated one month later (May 4, 2023, at 13:00 EST) to examine consistency over time. A period

[5] Prior to video export, researchers compared the search of a newly created TikTok account in comparison to a pre-owned account to test if TikTok's individually tailored algorithms influenced the videos displayed as top videos for a particular hashtag. There was no difference in videos between a control and pre-created account when searching a hashtag and viewing its top videos, therefore team members did not create new TikTok accounts to export videos. [2]There has not yet been research conducted on content decay on TikTok. However, in a study examining content decay across time on the social media site, Twitter, Asur et al. (2011) found content may fade in as quick as 20 min or persist for days. Findings suggesting a loglinear pattern of delay over 20–30 days informed the one-month duration between timepoints in the current study. We evaluated change over one month in accordance with this previously reported decay function, as no work to date has evaluated change in content on TikTok, specifically.

of one month was chosen to allow for significant change in content, as previous research suggests that some content may fade as quickly as 20 min or whereas others persist for days (Asur et al., 2011; on Twitter). No research has evaluated the rate of decay on TikTok, specifically. As such, we relied on the findings of Asur et al. (2011) from Twitter (now X) suggestive of a loglinear pattern of decay over 20–30 days to inform the one-month duration between timepoints in the current study. Following the exclusion of videos spoken in any language other than English ($n = 1$), duplicate videos were removed (see Fig. 1) resulting in a total sample size of $n = 275$ unique videos, $n = 155$ at T1 and $n = 120$ at T2.

Coding

Several domains of coding, including video-, creator- and content-related codes, were conducted for the subsequent analyses and can be found in Table 1. Variable selection was conducted collaboratively by all authors to ensure alignment with the study's aims and facilitate meaningful analysis of the research questions. Video-related variables (number of views, likes, comments, etc.) were selected to quantify user engagement. Creator-related variables were selected to capture information about the creators posting content under autism-related hashtags on TikTok, including how they identify themselves and the type of language they chose to use (ableist/non-ableist and identity-/person-first language). Similarly, content-related variables were selected to capture the overall topic of the content being shared and its valence. For a detailed breakdown of the codes, see Table 1. For all coding information, the codebook is available on Open Science Framework.

All videos were coded by two coders. Training was completed on 20 videos from the first video download. During training, additional codes were added, and some existing codes were more explicitly defined. Upon confirmation of the coding scheme and the completion of training, each coder independently coded each video, followed by a comparison of scores to assess the degree of interrater reliability. Interrater reliability was measured via intraclass correlations for continuous measures (video views, likes, comments, length, understandability and actionability) and weighted Cohen's Kappa for categorical measures (creator pronouns, source, subject, language; content topic and valence). Intraclass correlations (ICC's) were interpreted according to Koo and Li (20): $< 0.50 =$ *poor reliability,* 0.5–0.75 = *moderate reliability,* 0.75–0.9 = *good reliability,* and $> 0.9 =$ *excellent reliability*. Kappa values were interpreted according to (McHugh, 2012): 0–0.20 = *no to slight agreement*, 0.21–0.40 = *fair*, 0.41–0.60 = *moderate agreement*, 0.61–0.80 = *substantial agreement*, 0.80–1.00 = *almost perfect agreement.* Rater disagreements were resolved by consensus. Interrater reliability ranged from moderate to near perfect reliability depending on category and measures. All interrater reliability metrics are available in Tables S1 and S2.

Video information from each recording was extracted from screenshots of the exported videos. In addition to the date that the video was exported, coders recorded the date the video was uploaded, the hashtag in which it was exported from, the length of the video file, and the number of views, likes and comments at the time of export. For videos that appeared under, and thus exported from, more than one hashtag, coders randomly selected, from the corresponding hashtags, which hashtag the video would be coded under and removed duplicates from the sample.

Creator information was extracted from videos, captions, and profiles if available. Creator pronouns were extracted from the listed pronouns section or biography of creators' profiles. Researchers defined the creator "source" as the user who is posting and/or creating the video. The identity of the creator source was determined based on the user's profile (e.g., if the creator had "autistic" in their biography, they were coded as a self-advocate) and video content (e.g., if the creator's video included them talking about early signs of autism they saw in their child they were coded as a parent). The video subject – the individual or individuals who are in the video that

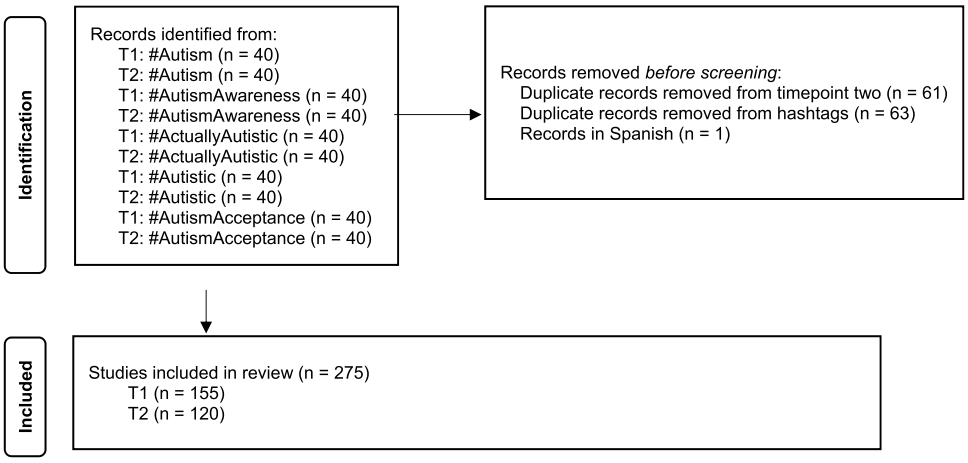

Fig. 1. Flowchart illustrating the search and download process for TikTok videos analyzed in the current study. Forty TikTok videos were downloaded from each of the top 5 autism-related hashtags at two distinct timepoints. Prior to screening, duplicate videos from timepoint two and individual hashtags were removed, along with two videos in Spanish. The final dataset comprised 275 videos: 155 from timepoint one and 120 from timepoint two.

Table 1
TikTok Content and Creator Coding Scheme.

		Codes	Definition
Video Information			
Hashtag	1	#Autism	
	2	#AutismAwareness	
	3	#ActuallyAutistic	
	4	#Autistic	
	5	#AutismAcceptance	
Creator Information			
Creator Pronouns	1	She/her	
	2	He/him	
	3	She/they	
	4	He/they	
	5	They/them	
	6	Other/any	
	7	Not Stated	
Creator Source	1	Self-advocate	Users who identified themself as autistic and/or autistic self-advocate in the audio or text of the video or in their user profile
	2	Professional/Coach	Users who identified themself as a healthcare professional, coach, or healthcare facility in the audio or text of the video or in their user profile
	3	Parent	Users who identified themself as a parent/guardian of an autistic child in the audio or text of the video or in their user profile
	4	Other	Users who could not be clearly classified as a self-advocate, professional/coach, or parent through the video, text, or user profile and/or users who did not fall into the aforementioned categories (e.g., a sibling or child of an autistic individual)
	5	Multiple Identities	Users who, through their video, video text, or user profile, identified themself as more than one of the coded identities (e.g., an autistic parent of an autistic child, an autistic healthcare provider)
Subject	1	Self-advocate	Video subjects included any individuals present at any point during the TikTok video. The categorization of video subjects was conducted following the same criteria as the creator categories above
	2	Professional/Coach	
	3	Parent	
	4	Other	
	5	Multiple Identities	
	6	Multiple Subjects	Videos with multiple individuals of varying identities (e.g., a video including both a parent and an autistic child)
Language Identity	1	Person-first	
	2	Identity-first	
	3	Mixed	
	999	N/A	
Ableist/ Nonableist Language	1	Ableist	
	2	Nonableist	
	3	Mixed	
	999	N/A	
Content Information			
Content Topic	1	Early signs	The overall theme of the video is related to "early signs" of autism and/or specifically listed early signs of autism. If a video contains a visual representation of an autistic trait but does not identify it as such (e.g., a parent showing their child sensory seeking without calling out sensory processing differences as a sign/trait of autism verbally or in text) code in lived experience.
	2	Lived experiences*	Videos describing or depicting the experiences of the creator, autistic subject, or a family member of an autistic individual
	3	Signs you're autistic	Videos listing signs of autism without further information on the listed signs. If a video contains a visual representation of an autistic trait but does not identify it as such (e.g., an individual talking about their difficulty with making eye contact during interactions with others without identifying difficulty with direct eye contact as an autistic trait verbally or in text) code in lived experience
	4	Psychoeducation	Videos aimed at educating the viewer about DSM-related autistic traits or statistics about autism
	5	Stims	Videos talking about or showing stims
	6	The side of autism you don't see	Videos in which creators verbally state or describe in text that the video is about "the side of autism you don't see" and videos describing their internal experiences (rather than their experience in the external environment)
Valence	1	Negative	
	2	Positive	
	3	Mixed	
	4	Neutral	

Note. * = The term "lived experiences" in this context typically refers to the experiences of an autistic individual. However, we did not restrict this category to self-advocates; thus, "lived experience" denotes the personal perspective with autism of the video creator or its subject, regardless of their classification.

the TikTok creator (creator subject) posted – was coded into the same categories using the same processing used for coding video's creator subject, with the addition of "multiple subjects" for videos that showcased more than one individual (e.g., a video with both an autistic child and their parent would be coded as multiple identities). Creator language use was coded for (1) identity-first vs. person-first and (2) ableist vs. non-ableist language; for examples, see Table S3 (Bottema-Beutel et al., 2021).

Similar to creator information, video content was extracted from videos, captions, and profiles, if available. Coding definitions of video topics can be found in Table 1; all videos were coded to a single topic category. If, during individual coding, a coder believed a video could fit into more than one topic, they selected the code that the content had most overlap with the defined coding criteria as the "primary" code and noted the potential "secondary" code in the coding document. During the consensus process, all videos with noted secondary topics were rewatched by both coders and discussed, with a final code assigned based on mutual agreement. Video valence was defined as the overall "tone" of the video (positive, negative, mixed). If the video included both positive (e.g., a parent talking about their child's strengths) and negative (e.g., a parent talking about autism-related difficulties their child has faced) content, the video was coded as "mixed" valence.

Videos were also assessed for Understandability and Actionability using the Patient Education Materials Assessment Tool for Audio/Visual materials (PEMAT-A/V; (Shoemaker et al., 2014). The PEMAT-A/V is a validated instrument used to assess how easy to understand and actionable audiovisual patient education materials are for a lay audience (Shoemaker et al., 2014). Each TikTok video was coded for understandability ($n = 13$ items) and actionability ($n = 4$ items). Each PEMAT-A/V statement is scored as 0 ("disagree") or 1 ("agree"). Understandability and Actionability are reported in percentages, wherein scores are averaged across construct items. For three understandability codes related to organization of materials, videos were given a code of "NA" if videos were under 1 min in duration, which comprised 75 % (205/275) of the overall videos. The PEMAT-A/V does not recommend any cut-offs to determine high, medium, or low understandability or actionability; instead, they are intended to be interpreted within the context of the research study or investigation. Thus, the PEMAT-A/V values obtained in the current study will be interpreted independently and in comparison to previous literature (Brown et al., 2024).

Post-hoc categorization

After following the above coding procedure, an overwhelming number of videos were related to one specific topic: lived experiences. To better understand the heterogeneity within this coding category, authors conducted further post-hoc coding of this video category ($n = 215$) to examine types of lived experiences conveyed in videos (post-hoc category definitions and video examples are available in Table 2). Post-hoc coding followed the same structure as described above: an initial 20 % of the sample of lived experience videos was independently reviewed by the research team, led by an autistic coder, to identify recurring patterns and thematic content. Through discussion and comparison, preliminary themes were refined and structured into four distinct subcategories. The remaining 80 % of videos were independently coded and compared to establish interrater reliability (IRR = 0.85). Upon completion of coding, rater disagreements were resolved by consensus.

Results

Video information

The final sample included $n = 49$ #autism videos (17.8 %), $n = 47$ #autismawareness videos (17.1 %), $n = 64$ #actuallyautistic videos (23.2 %), $n = 60$ #autistic videos (21.8 %), and $n = 55$ #autismacceptance videos (20 %). Video duration ranged from 5 s to 4.5 min ($M = 47.39$ s; $SD = 43.93$), received between 999 and 5.26 billion views ($M = 3930{,}767$; $SD = 7877{,}181$), 203–9.5 million

Table 2
Definitions and Examples of Post-hoc Categorization of Lived Experience Videos.

Category	Definition & Examples
Signs/Traits	Visual representation or discussion of broad autistic traits and/or how they affect one's lived experiences. "When I get caught having an autism moment" "Things I thought were bad personality traits but were actually just autism" "Autism in girls"
Neurotypical vs. Autistic Experiences & Interactions	Comparing experiences of autistic and non-autistic people, camouflaging, and discussion of lived experience of autistic people in a world designed for non-autistic people. "I think why it is so hard for neurodivergent people to get neurotypical doctors to believe them when they something is wrong…" "What being masked for 20 years does…" "You don't seem autistic to me…"
Diagnostic Process & Accommodations	Discussion of anything related to diagnostic process (e.g., personal road to receiving a diagnosis, reasons for or against diagnosis, self-tests) and discussion of accommodations. "This is the story of how I found out I was autistic" "Amusement park autism accommodations" "Making my family take the tism test Thanksgiving…"
Not Applicable	Videos not related to autism or videos depicting an individual who is not identified as autistic without mention of anything related to autism.

likes ($M = 538{,}481$; $SD = 1227{,}133$), and 0–68,600 comments ($M = 4577$; $SD = 8626$).

Creator information

Most creators (61.8 %) were self-advocates, followed by parents (15.6 %) and other (e.g., non-parent family members of autistic individuals, reposting accounts, and creators who could not be explicitly identified; 15.6 %). Only 3.6 % of creators were professionals/coaches and 3.3 % held multiple identities. About half of creators (52 %) listed their pronouns in their profile ($n = 143$). The 52 % of reported pronouns comprised, 38.5 % she/her, 26.6 % she/they, 7 % he/him, 2.8 % he/they, 11.9 % they/them, and 13.3 % used other pronouns or indicated they were okay with "any."

Language

Of videos that used person- (person/child with autism) or identity-first (autistic person/child) language ($n = 193$), 80.8 % used identity-first language while 10.9 % used person-first, 8.3 % used a mix of both. Similarly, of $n = 231$ videos that used ableist or nonableist language, 70.6 % used nonableist, 8.2 % ableist, and 21.2 % a mix of both. Differences by content creator emerged; self-advocates were significantly more likely to use non-ableist (75 %) and identity-first language (85.9 %) compared to parents (56.3 % non-ableist, 59.1 % identity-first), $X^2 = 21.23$, $p < .001$. Likes, comments and views did not differ by the type of language use ($p > .05$).

Content

Across the entire sample, the most common video topic under autism-related hashtags was lived experiences (75.7 %). The remaining videos fell relatively equally across remaining topics: signs you're autistic (8.8 %), the side of autism you don't see (6.1 %), early signs of autism (4.4 %), stims (2.8 %) and psychoeducation (2.2 %). Examples of videos coded under each category are available in Table 3. Although lived experiences were the most common topic among all creator types, parents were significantly more likely to create content related to early signs of autism, the side of autism you don't see, and stims, compared to other creators, $X^2 = 46.86$, $p < .001$. Despite all creators presenting relatively similar content around lived experiences, self-advocates were significantly more likely to present negative content compared to other creators, $X^2 = 26.01$, $p < .001$. The valence of TikTok videos was most often positive (30.2 %) or mixed (30.5 %), negative (19.6 %), then neutral (19.6 %).

With 75.7 % of videos falling under lived experiences, authors re-coded videos in the lived experience category into four subcategories (Table 2): discussion or visual representation of broad autistic traits (40 %), representation of interactions or differences between autistic and non-autistic people (34.9 %), diagnostic process and accommodations (9.3 %), and videos not directly related to autism (15.8 %). The majority of lived experience videos (61.4 %) were posted by self-advocates ($n = 132$), while the remaining 38.6 % of videos were posted by creators whose identities could not be adequately identified ($n = 39$), parents ($n = 30$), creators with multiple identities ($n = 8$), and professionals/coaches ($n = 6$). Of the videos posted by creators other than self-advocates ($n = 215$), 34 % featured an autistic individual as the subject. In contrast to videos in all other subcategories, most often posted by self-advocates, videos not directly related to autism were posted most often by creators classified as "other" ($X^2 = 55.69$, $p < .001$; e.g., non-parent family members of autistic individuals, reposting accounts, and creators who could not be explicitly identified) and comprised 12.4 % of the overall sample. About 87 % of lived experience videos posted by parents featured their autistic child and over half (56.7 %) were related to signs and traits of autism. In contrast to videos posted by parents that were categorized as "early signs" or "signs you're autistic", these videos showed the autism-related traits of their children (e.g., focused interests), described experiences of their autistic child, or captured experiences of parenting. All eight creators who had multiple identities (i.e., fell under more than one coded identity) and posted a lived experience video were autistic and created content related to their diagnostic pathways, masking, and interaction experiences with non-autistic individuals. Of the six videos posted by professionals/coaches, four were posted by accounts

Table 3
Examples of TikTok Video Content Categories.

Content Category	Examples
Early Signs	"Early signs of autism I saw in my daughter's first two years." "Early signs of autism may look like…"
Lived Experiences*	"When I get caught having an autism moment." "My autistic son omg look what he's done. He's overcome his biggest fear."
Signs You're Autistic	"Here are some signs of autism you didn't know about." "Random things I didn't know were autistic traits."
Psychoeducation	"Stats show that autism prevalence increased by 178 % between 2000 and 2016." "What the autism spectrum actually is."
Stims	"AuDHD masked stimming." "Things I've always done that I didn't realize was stimming"
The Side of Autism You Don't See	"One thing that is frustrating for me with being autistic is the constant confusion that I experience. People really underestimate the exhaustion that comes with being constantly confused." "I wanted to show you guys the other side of having an autistic child."

Note. * = Lived Experience subcategory codes and examples are reported in Table 2.

who identified themselves as autism-related societies, services, or foundations and showcased an autistic individual talking about their experience.

Understandability and actionability

PEMAT-A/V understandability for videos on average was 98.3 % ($SD = 0.06$) and actionability was an average of 1.6 % ($SD = 0.10$). Videos with low understandability scores tended to have muffled audio or pictures covering text on the screen.

Differences over time

A total of 61 duplicate videos (30.5 % of the T1 $N = 200$) were found during the T2 data pull, suggesting a moderate amount of stability in video content over one month. Chi Square tests were used to probe for significant differences in creator source, pronouns, language use, content topic, and valence, between the unique T1 ($n = 155$) and T2 ($n = 120$) videos. Results suggested no significant differences across all metrics of interest, $ps > .05$ (Table 4). In other words, although a significant amount of turnover and decay in content (~70 % new content) occurred over 30 days, the proportion of content creator identities, prevalence of language use, and core topics remained the stable.

Discussion

The aim of the current study was to characterize the content, creators, and language of videos subsumed under the five most frequently used autism-related hashtags across two timepoints, one month apart. By exporting videos at two timepoints, this allowed us to evaluate whether the information observed during T1 was transient, or whether it was representative of the average viewing day.

Table 4
Content and Language Differences Across Timepoints.

	T1 April 4, 2023	T2 May 4, 2023	X^2
Total (n)	155	120	
Creator Source			.649
Self-advocate	91	79	
Professional/Coach	9	1	
Parent	24	19	
Other	29	14	
Multiple Identities	2	7	
Creator Pronouns			.261
She/her	35	20	
He/him	6	4	
She/they	17	21	
He/they	3	1	
They/them	7	10	
Other/any	11	8	
Not listed	76	56	
Language Identity			.335
Person-first	13	8	
Identity-first	86	70	
Mixed	13	3	
Not applicable	43	39	
Ableist/Nonableist Language			.181
Ableist	11	8	
Nonableist	85	78	
Mixed	33	16	
Not applicable	26	18	
Content Topic			.387
Early signs	2	7	
Lived experiences	123	92	
Signs you're autistic	13	5	
Psychoeducation	10	3	
Stims	2	4	
The side of autism you don't see	4	9	
Missing	1		
Valence			.467
Negative	23	31	
Positive	53	30	
Mixed	51	33	
Neutral	28	26	

Note. T1 = First Timepoint, T2 = s Timepoint, approximately 30 days apart. None of the Chi Square values presented reached a-priori levels of significance ($ps > .05$).

Results suggested there were no significant differences in all dependent metrics of interest between videos at two time points, despite 70 % of the content downloaded at T2 being new. Considering the fast-changing nature of TikTok content in tandem with TikTok's advanced algorithms designed to specifically cater to each unique user's "For You Page" (Jargon, 2022), the absence of significant changes in content characteristics across 30 days may be indicative that there are certain characteristics of content that are more commonly promoted or engaged with on TikTok, such as content from autistic self-advocates about lived experiences. Another interpretation is that content decay on TikTok is longer than on other social media platforms; however, given we only observed that 30 % of content was stable across time points, our research suggests the turnover of new content is similar to other sources (Asur et al., 2011). Despite 70 % representing new videos, the themes, content, valence, and language in autism TikTok remained similar over time. As a result, the metrics of interest will be discussed below, collapsing across time points.

Video creators

Consistent with previous research (Aragon-Guevara et al., 2023), autism-related TikTok videos were primarily posted by autistic self-advocates (61.8 %) and parents (15.6 %). The high prevalence of self-advocates and parents of autistic children may point to TikTok's primary purpose being to foster a sense of community among autistic individuals or families of autistic youth, a theme aligned with current research on autistic identity and TikTok (Alper et al., 2023). When considering who was represented in TikTok content, it is also imperative to consider who was *absent.* No TikTok content included in the current study was created by non-speaking/minimally verbal individuals, or individuals who use augmentative and alternative communication (AAC). Underrepresentation of those who may be classified as "profoundly autistic" or high support needs (Lord et al., 2022) is a noted problem in research contexts (Clarke et al., 2024; Lord et al., 2022; Vivanti, 2024), which has extended to media portrayals of autistic presentations (Nordahl-Hansen & Øien, 2021; Vivanti, 2024). As noted by Vivanti (2024) "media portrayals privilege manifestations of autism that are less dissimilar to neurotypical standards of ability" (p.754), which our current results corroborate.

For autistic individuals who may not use verbal communication modalities, parents often use their voices to advocate on their child's or adult's behalf (Boshoff et al., 2018), a phenomenon represented on TikTok by large proportion of parents whose lived experience videos feature their autistic child. Parental perspectives were present throughout the current investigation, representing ~15 % of autism-related TikTok content. Although we did not specifically look at the support needs of the children represented by their parents or caregivers in the video, it is assumed that non-speaking individuals and "profoundly autistic" individuals remain notably absent or under-represented. Even if all parenting videos were created by parents supporting their non-speaking child, this would, at most, reflect only 15 % of the autism content, when estimates of those with high support needs represent closer to 30 % of those on the spectrum (Hughes et al., 2023; Clarke et al., 2024). Taken together, although TikTok appeals to autistic self-advocates and those wishing to find community in autism, the representation of all autistic individuals is lacking on this social media platform.

"AutisTiktok" creators are also different from established prevalence in another core way: gender diversity. Although only half of the sample reported their pronouns, in those who reported their pronouns, there was a higher percentage of she/her and she/they pronouns users in comparison to he/him and he/they pronoun-using-creators. This skewed proportion towards she/her and she/they creators may paint an inaccurate depiction of the current male-to-female ratio of autism in the general population vs. on TikTok (Maenner, 2023). Although the historic male:female ratio of autism is weighted towards males, recent research endeavors sought to uncover the "leaky pipeline" of autistic females (D'Mello et al., 2022; Lai & Baron-Cohen, 2015) and prevalence estimates show a steady increase of autistic females diagnosed over time (Harrop et al., 2024; Russell et al., 2022; Shaw et al., 2025). Further, research has highlighted reasons why females are missed, late or mis-diagnosed (e.g., use of primarily male-centric diagnostic criteria, female social strengths, female camouflaging or masking; for a review, see McFayden et al., 2023). Thus, the representation of those who identify themselves using she/her or she/they pronouns may reflect the rising number of recently-diagnosed, late-diagnosed or self-diagnosed autistic females (Bargiela et al., 2016; A. S. Russell et al., 2024). Although these findings may be influenced by gendered social media use (Perrin, 2015; Twenge & Martin, 2020), they are likely to influence the lay public's perception of autism.

In addition to the high prevalence of she/her and she/they content creators, the majority of creators (54.6 %) used pronouns other than the societally-binarized she/her and he/him (these pronouns accounted for 28.4 % of the total sample), which aligns with the higher prevalence of gender diversity reported within the autistic community (Corbett et al., 2023; Sala et al., 2020; Strang et al., 2023). The number of gender diverse autism-related content creators may even be greater than the estimated 54.6 % observed here since pronoun use alone is not a comprehensive measure of gender diversity; for example, of users who used she/her or he/him pronouns ($n = 65$), three reported being transgender in their TikTok biography, all of which were trans men, and thus would also be considered within a gender diversity perspective.

Our findings differ from the only other study examining creator gender (Gilmore et al., 2023) who found the majority of autism-related TikTok content creators were masculine and feminine "presenting," with only 14 % of their sample falling under non-binary presenting or unknown. Importantly, this study relied on perception of creator gender, which is subject to bias. Novel work out of Australia, which is currently in preparation for publication, coded content creator pronouns and also found a majority of female content creators presenting autism-related information on TikTok (Zheluk & Stammmers, 2024), which aligns with our reported findings. The high frequency of gender diverse pronoun use in the current study supports the importance of extracting gender from self-report rather than perception alone, as gender identity often does not align with gender expression (Watson, 2019) and classification by coder perception alone may not accurately measure creator gender. Although autistic creators on TikTok may not be representative of autistic people as a whole, better understanding who is creating autism-related TikTok videos has implications for understanding how autistic people and autism may be perceived on this popular social media site and who in the autistic community is utilizing TikTok to create content and/or connect with other users.

Language

Examination of language use (ableist vs nonableist, person-first vs. identity-first) in autism-related TikTok content expanded prior autism TikTok research and focused on domains that are important to autistic self-advocates (Monk et al., 2022; Taboas et al., 2023). Overall, language use reflected the preferences of autistic self-advocates: identity-first, nonableist language (Bottema-Beutel et al., 2021; Bury et al., 2023; Taboas et al., 2023). Of course, language preferences are not universal nor one-size-fits all, which is reflected in research on language preferences in the autistic community and is reflected in the diversity of language use on TikTok (Bottema-Beutel et al., 2021; Bury et al., 2023; Taboas et al., 2023). Self-advocates were significantly more likely to use both nonableist and identity-first language than parents, a trend that has been reflected in research on the topic, wherein parents show a stronger preference for person-first language compared to adults (Buijsman et al. 2023). The differences in language preferences between autistic adults and parents of autistic youth may emerge for several reasons, including generational differences, knowledge of language practices within the community, and in-group "privilege". In other words, parents may not feel comfortable using identity-first language for their child if their child is not of age to dictate their preferences; thus, using person-first language may feel like a safer alternative in the eyes of caregivers. Alternatively, previous literature has indicated that autistic authors may be more likely to use 'tentative language' (e.g., "seem", "may", "might", "not sure") as a way of avoiding social threats, or in response to negative feedback on social media sites (Koteyko et al., 2025). Thus, autistic creators may present with a unique linguistic phenotype in a way that was not captured here.

Additional considerations for language use include geography and cultural norms (Buijsman et al. 2023). In cultures that place value on conformity, for example, celebrating the individual differences inherent to the neurodiversity movement may not be as acceptable or preferred (Kapp et al., 2013). All videos in the current study were English, and although cultural variations of English are certainly present, future research may wish to uncover geographic and cultural differences in language use on autism social media platforms.

As language is an ever-evolving discussion in the neurodiversity movement, TikTok may represent an excellent finger on the pulse on the current language preferences of the autistic community. Furthermore, the specific language use of the majority of TikTok content may inform how a lay audience communicates about autism or with autistic individuals. Language use on social media is often recursive and cyclical (e.g., a word is popularized on social media, which becomes more common in live communication, which then changes its use and interpretation in social media), which means linguistic terms may change in popularity or acceptability. Interestingly, using a research-based paradigm to capture social media language use might be too 'dated', or lack external validity, to accurately reflect the language trends in the autistic social media space. Future work may wish to evaluate the language patterns without fitting it to a retrospective mold but instead using a deductive approach to study language use in autism spaces.

Video content

In comparison to other forms of social media (Bakombo et al., 2023; Kim et al., 2022), our findings confirm that the purpose of autism TikTok content is to serve as a community for autistic individuals to explore their autistic identity. This conclusion is drawn from the overwhelming majority of videos that were coded under the "lived experiences" domain, underscoring that TikTok appears to be used to share similar life experiences to engender a sense of community. Self-advocates' greater tendencies towards sharing content with negative valence may point to their willingness to discuss the multi-faceted nature of the autistic experience (McDermott, 2022). This may be an important resource for many autistic individuals, particularly as sense of community can serve as a protective factor for autistic individuals' mental health (Bakombo et al., 2023; O'Reilly et al., 2019). Lived experience videos posted by self-advocates focused on how their autistic traits influenced their experiences and interactions with non-autistic individuals. While the intention of posting these lived experience videos may not be psychoeducational in nature, they may serve a similar purpose through exposing non-neurodivergent TikTok users to common experiences of autistic individuals navigating a neurotypically oriented society (McDermott, 2022). Furthermore, the overwhelmingly low proportion of videos explicitly focused on psychoeducation may be explained by this concept of experiential learning – wherein individuals acquire knowledge through observing and reflecting on others lived experiences. Although a small percentage of parents shared content related to their experiences or the lived experiences of their child, in comparison to self-advocates, parents produced content largely focused on "early signs of autism" and "the side of autism you don't see." This focus on identification-related content may represent parents' preferences to use TikTok as a medium to share informative information with other parents of neurodivergent children. It is important to take into consideration that 12.3 % of the analyzed videos were not related to autism, underscoring work from Aragon-Guevara and colleagues (2023) that highlights the presence of inaccurate, or un-related, content related to autism on TikTok.

Understandability and actionability

Given the use of social media for finding community or seeking health-related information (Fergie et al., 2016; Mazurek, 2013; Triantafyllopoulou et al., 2022), it is imperative to evaluate how comprehensible and actionable information gathered from TikTok is for a lay audience. Our results used a well-validated checklist to score videos on understandability (how comprehensible they are to a lay audience), and actionability (how much do they spur or promote action). Replicating the findings of Brown et al. (2024) and Mantas et al., (2024) who also used the PEMAT-A/V to rate TikTok videos, "AutisTikTok" videos were understandable, but not actionable. This profile of scores supports findings related to video content in highlighting that the purpose of autism-focused TikTok being a place for community rather than a call to action or place for individuals to find resources. Furthermore, the high

understandability ratings from the PEMAT-A/V evidenced across studies (Berg Egge & Gabarron, 2024; Brown et al., 2024) demonstrates that TikTok is a user-friendly experience for viewers with differing reading comprehension levels or visual processing differences. As several of the scoring metrics on the PEMAT-A/V involve accessibility (e.g., large font, closed captions, background music at an appropriate volume), the consistently high understandability scores across our findings and two other works suggest that TikTok is a friendly platform for those that may need additional supports to engage with audiovisual content. These factors together paint a clear rationale for the rise in popularity of TikTok videos among young adults.

Limitations

Our findings must be considered in light of limitations. First, there is a wide variety of autism-related hashtags that may produce a different range of content that may be informative for future research. However, given the number of duplicates removed between hashtags, it appears a common practice to include multiple hashtags for each video. Thus, it is likely that many of these subgroups of autism hashtags (e.g., #audhd) were also captured in our search. Second, duplicate videos that fell under multiple hashtags were randomly assigned to a single hashtag for analysis. Due to many videos using multiple hashtags, we were not able to examine group differences between hashtags. Lastly, characteristics that "hold" top positions may vary in variables evaluated here, or may be due to other variables not evaluated, such as a "trending" soundbite. However, by including the videos as they show up under each of the five most popular autism hashtags, regardless of the number of views or likes, we believe our sample is representative of autism-related content on TikTok.

Conclusion

This study adds to a small, yet growing, body of research characterizing autism-related content on TikTok. We analyzed the trending videos under the top five autism-related hashtags on TikTok to characterize the type of content, creator, and language and its understandability/actionability. Overall, TikTok videos related to autism, at large, are posted by autistic self-advocates, about lived experiences, use identity-first, nonableist language, were understandable to lay users, and retain these characteristics over time with low rates of decay. Future research should prioritize the self-reported demographic makeup of autistic creators, as well as closer examination of the type of content created within specific groups of creators (parents of autistic children, non-speaking/minimally verbal individuals, LGBTQ+ autistic individuals, autistic people of color) to better understand what the algorithmically driven "For You Page" may look like for individuals who identify with one or many of these groups. An accurate understanding of the characteristics of autism-related TikTok content is important for researchers, clinicians, and autistic individuals alike to better navigate and utilize this popular social media platform in a way that is advantageous and supportive for the autistic community.

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Clare Harrop: Writing – review & editing, Writing – original draft, Supervision, Resources, Methodology, Investigation, Formal analysis, Conceptualization. **Amanda Neal:** Writing – review & editing, Data curation, Conceptualization. **Abbigail Waycaster:** Writing – review & editing, Validation, Data curation, Conceptualization. **Tyler McFayden:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Formal analysis, Conceptualization. **Maia Karpinsky:** Writing – review & editing, Writing – original draft, Visualization, Validation, Project administration, Investigation, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

The authors declared no potential conflicts of interest with respect to research, authorship, and/or publication of this article.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.reia.2025.202720.

Data availability

Data will be made available on request.

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