“HERE TO HAVE FUN AND FIGHT ABLEISM”: #AUTISKTOK USER BIOS AS NEUROQUEER MICROACTIVIST PLATFORM AFFORDANCES

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Introduction and Theoretical Background

User biography sections on digital social platforms (hereafter described as “user bios” or “bios”) are spaces for account holders to communicate their identities to other users and interlocutors. In doing so, users take narrative ownership by “storying” the mediation of identity. User bios are a platform affordance (DeVito et al., 2017; Bucher & Helmond, 2017) encouraging communication of the self.

Bios may include hashtags, slang influenced by algorithmic culture (i.e., “algospeak”), or emojis to share important qualities of how one wants to be perceived (Steen et al., 2023). For instance, social media users often rely on emojis as a self-branding practice to convey interests and identity markers within the constraints of a respective platform’s character limits (Li et al., 2020). There is a lack of research, however, on the specific role of user bios on TikTok, a micro-vlogging and content creation platform popular among youth, particularly those from historically marginalized groups.

Online platforms, such as social media, are increasingly used as community hubs for disabled groups, and especially for autistic people (Rauchberg, 2022; Alper, 2023; Guberman, 2023; Sins Invalid, 2019). We focus on #Autisktok, one of many enclaves for autistic community building and cultural production on TikTok. Hashtags are a commonly used affordance on TikTok, in addition to other content sharing and social media platforms (e.g., Twitter). They serve multiple purposes, as they are archival and searchable (Herrman, 2019), provide a name for a community space, and are indicators of identity (Hererra, 2018). Additionally, they can be organizational (Dailey, 2023) and storytelling elements of ad-hoc networked publics (Bruns & Burgess, 2011) whose meanings change and evolve over time (Papacharissi, 2015).

Through a critical/cultural qualitative thematic analysis of #Autisktok user bios, we assess how the user bio is a space for mediating self-advocacy, agency, and autistic-centered knowledges on #Autisktok. To investigate how autistic TikTokers use their profile’s bio section as a space for “restorying” (i.e., taking back narrative ownership) mainstream discourses about autism and agency, we draw upon M. Remi Yergeau’s (2018) work on autism and neuroqueer rhetorics. Through their use of neuroqueerness, Yergeau challenges clinical framings of autism that place it outside of neurotypical conceptualizations of language and culture. Neuroqueer rhetorics “are stories about communication more generally… [and] disability cultures… and what or who is determined to be storied or storyable” (p. 21).

Our inquiry is equally informed by Arseli Dokumaci’s (2023) theory of microactivist affordances, or disabled peoples’ improvisational tactics within inaccessible physical environments. We extend Dokumaci’s framework toward the digital, examining how the micro-activist platform affordances of the TikTok user bio allow autistic youth to mediate neuroqueer subjectivities beyond ableism.

We pose the following research questions: How do autistic youth use the bio section on TikTok to (re)story autism diagnosis? What is the user bio’s role in creating a supportive enclave for other autistic creators, users, and activists on the TikTok platform?

**Method**

Our study employs a mixed-methods approach using computational and critical qualitative methods. The project is grounded in critical/cultural studies to investigate the enmeshed relationship between discourse and dominant ideological structures (see Ono, 2009). We obtained IRB approval from Northeastern University to begin data collection. Our research team (composed of neurotypical and neurodivergent researchers) began with an exploratory walkthrough (Zulli & Zulli, 2020) of autism-related hashtags on TikTok and other social media platforms. Through this, we discovered an English-language account on Instagram dedicated to reposting “actually autistic” TikToks, and created a dataset based on this corpus. One team member contacted the account holder but did not receive a response. We have anonymized the account handle to protect their identity.

We first used a Python scraper to pull data (e.g., captions, comments, URLs) from 1,093 Instagram posts from September 2020 to June 2022, and reconstructed the data
set after reconciling posts with their source material on TikTok. In January 2023, we engaged in a qualitative thematic analysis (Basu, 2017) of the corpus focused on the biography sections of the 639 unique and available TikTok posts (e.g., had not been deleted by TikTok users after having been reposted to Instagram).

With respect to positionality, our research team has varying individual relationships to autism diagnosis; one author identifies as autistic, and two others as neurodivergent. Our teams’ collective expertise in social media research and lived experience with neurodivergence were assets as we collected and analyzed our data. Using an open and selective coding process, our thematic analysis produced 3 primary and 7 secondary codes. The code sets were collectively compared and developed into 3 themes: explicit use of autism in bio, autism and intersecting political identities, and the bio as a space for asserting autistic selfhood.

Findings

**Explicit use of autism in bio**
Social platform users often mediate their identity to other account holders through their account’s biography section (Li et al., 2020; Greene & Brownstone, in press). #Autistok users also employ the biography section on their TikTok profiles to discuss their connections to autism and the self publicly. Users in our corpus included popular terms like “Autistic” (appearing 43 times), “#ActuallyAutistic” (6 times), “neurodivergent” (6 times), and “neurodiverse” (3 times). Additional account bios featured unique, playful phrases that convey the user’s interpretation of their autistic experiences (e.g., “soft autism content,” “autistic goth,” and “neuroqueer”).

**Autism and intersecting identities**
Several user bios in the corpus discuss autism alongside other intersecting identities, suggesting that, for #Autistok users, autism shapes how they experience other identities, such as race, gender, and sexuality. User bios discussed the intersections of autism with other disabilities (e.g., “Autistic & ADHD/AuDHD,” “Autism & DID [Dissociative Identity Disorder] system,” “Autistic & chronic pain”); autism, gender, and sexuality (e.g., use of 🏳️🌈 emojis in bio, “your favorite queer autistic vegan,” “autistic & ace,” “nonbinary goblin”); and autism and race (e.g., “autistic & Black,” “bisexual, biracial, bilingual,” “Black, autistic, & LGBTQ”). Notably, the bios of white autistic users in the corpus did not discuss racial identity.

**The bio as a space for asserting autistic selfhood**
Some user bios additionally communicate specific information about access needs or (humorous) narrativizations of autistic experiences, reflecting self-expressions of agency often denied to autistic people. Bios were used to indicate access needs regarding interaction (e.g., “tone indicator appreciated,” “semi-speaking,” “AAC user”2) and to discuss diagnosis (e.g., “Late identified/late dx”). In addition, users often relied on abstract, Gen-Z style humor or euphemisms in their bios to story autism away from ableist, pathologizing rhetorics (e.g., “here to have fun and fight ableism,” “autism is winning bois,” “autistic bimbo”).

Conclusion
This work extends and builds upon work at the intersections of identity and societal marginalization, social media cultures, and platform politics. Our study illustrates how autistic creators use their account bios as microactivist platform affordances to engage in discourses of resistance that employ neuroqueer rhetorics, thereby re(storying) autism.

Notes

1. The #ActuallyAutistic hashtag and movement were created on Tumblr in response to the saturation of non-autistic users perpetuating anti-autistic ableism under the #Autism hashtag to reclaim narratives about autism and validate autistic experiences and knowledges (Osorio, 2020).

2. Augmentative and Alternative Communication (AAC) refers to a range of practices, tools, and devices that support verbal communication for non- and semi-speaking people.

References


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