

# Diagnosis Based on Content: The Role of Social Media in Late Autism and ADHD Self-Identification Among Adults in the UK

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## Abstract

*A rapidly expanding phenomenon has emerged at the intersection of social media culture and neurodevelopmental health: adults in the UK are increasingly exposed to autism and ADHD-related content on platforms such as TikTok, Instagram, and YouTube, prompting self-identification as autistic or ADHD prior to or instead of a formal clinical diagnosis. This paper presents a systematic narrative review of the literature on social media-mediated self-identification, synthesising evidence from digital sociology, clinical psychology, disability studies, and communication research. Drawing on the neurodiversity paradigm, identity-based models of late diagnosis, and the concept of diagnostic drift, the review examines the accuracy, risks, benefits, and equity implications of social media as an informal pathway to the recognition of neurodivergent identities. Four key tensions are identified: epistemic legitimacy versus clinical accuracy; community affirmation versus misinformation; empowerment versus exploitation; and digital access versus diagnostic inequity. The analysis contends that social media self-identification is neither wholly beneficial nor entirely harmful but constitutes a structurally significant response to persistent NHS under-diagnosis, prolonged waiting lists, and the historical exclusion of women, Black, and minority ethnic individuals from diagnostic frameworks. Policy implications for NHS England, social media platforms, and the autistic community are addressed.*

**Keywords:** *autism, ADHD, late diagnosis, self-identification, social media, TikTok, neurodiversity, diagnostic inequity, NHS, identity, UK*

## 1. Introduction

TikTok currently hosts extensive autism- and ADHD-related content, with the #autism hashtag alone generating approximately 11.5 billion views, and it predominantly features experiential, identity-focused material rather than formal educational content (Aragon-Guevara et al., 2023; Gilmore et al., 2023). In the context of prolonged waiting times and limited provision within UK neurodevelopmental services where adult ADHD and autism pathways are widely characterised as overstretched and at crisis level (Smith et al., 2023; Young et al., 2021; Maciver et al., 2025) social media has filled this diagnostic gap, not as a clinical tool, but as a cultural space where adults encounter lived experiences, language, and communities that

facilitate recognition of autistic or ADHD traits (Alper et al., 2023; Leveille, 2024; McMillan, 2025; Leiser et al., 2024).

This paper critically examines social media-mediated self-identification as a large-scale phenomenon arising from constrained access to diagnostic services and the growth of online neurodivergent cultures. The significance of this topic is threefold. First, autism and ADHD remain substantially under-recognised in adults, with expert groups documenting persistent under-diagnosis and unmet need in the UK (Young et al., 2021; Smith et al., 2023). Second, the phenomenon raises fundamental questions about diagnostic authority and epistemic legitimacy, as platforms such as TikTok facilitate practices of platformed diagnosis and identity work that coexist with, and sometimes

challenge, clinical frameworks (Alper et al., 2023; Leiser et al., 2024). Third, issues of equity are central: girls and women with autism and ADHD are more frequently overlooked or diagnosed later, partly due to gendered expectations and subtler, masked presentations (Loomes et al., 2017; Lai et al., 2021; Hinshaw et al., 2021), while Black and other racialized children are less likely to receive an autism diagnosis even when presenting with similar features (Mandell et al., 2009; Diemer et al., 2022). Recent research on TikTok demonstrates that minoritised neurodivergent communities, including South Asian diasporic users, utilise the platform to articulate intersectional experiences and construct marginalised neurodivergence that has been inadequately addressed by traditional systems (Alper et al., 2025; Diemer et al., 2022; Gilmore et al., 2023).

Accordingly, this paper does not seek to determine whether social media self-identification is inherently right or wrong. Instead, it explores the significance of this phenomenon, its emergence during a period of service failure and increasing online neurodivergent visibility, and its implications for clinical services, digital platforms, and policymakers (Young et al., 2021; Smith et al., 2023; Leiser et al., 2024).

## 1.1 Research Questions

This review is guided by the following questions:

1. What does the emerging literature tell us about the accuracy, prevalence, and nature of social media-mediated autism and ADHD self-identification?
2. What are the primary benefits and risks documented in the literature?
3. How does the phenomenon intersect with existing inequities in neurodevelopmental diagnosis?
4. What are the implications for NHS policy, platform governance, and clinical practice?

## 2. Background and Context

### 2.1 The Late Diagnosis Landscape in the UK

Autism and attention-deficit/hyperactivity disorder (ADHD) are lifelong neurodevelopmental conditions. Historically, both have been diagnosed predominantly in childhood and disproportionately among white boys whose difficulties present as externally observable behaviours (Baron-Cohen, 2009; Kildea et al., 2011). This narrow diagnostic focus has left many groups under-recognised, including women and girls who mask effectively (Bargiela et al., 2016), people with high intellectual ability whose compensatory strategies obscure day-to-day impairment (Livingston et al., 2019), and Black, Asian and minority ethnic individuals whose presentations have been differently pathologised or not assessed at all (Sturm et al., 2017).

Late or missed diagnosis is linked with higher rates of anxiety and depression, reduced access to appropriate workplace adjustments, greater vulnerability to exploitation and abuse, and a persistent sense of not understanding oneself (Crane et al., 2019). In the UK, the mean age of autism diagnosis for women is reported to be over 40 years (Lai et al., 2015), indicating that many navigate education, employment and relationships for decades without the self-knowledge or structural support that a timely diagnosis can offer.

NHS England's adult neurodevelopmental diagnostic pathway is widely recognised as being in crisis. A recent parliamentary report found that average waiting times for adult autism assessments had tripled between 2019 and 2023, with marked regional variation and particularly limited provision for adults without intellectual disabilities (House of Commons Health and Social Care Committee, 2023). The NHS Right to Choose mechanism, which allows patients to seek NHS-funded assessment from independent providers, offers a partial workaround for those with the required knowledge and advocacy capacity, but access to this route is itself unevenly distributed.

Within this context, social media mediated self-

identification should be interpreted as a rational response to systemic shortcomings in reaching a substantial portion of the population, rather than as a frivolous or irresponsible shortcut.

Since around 2019, the rapid growth of neurodiversity affirming content on platforms such as TikTok, Instagram and YouTube has marked a qualitative shift in public discourse about autism and ADHD. Earlier online autistic communities, notably text-based forums such as WrongPlanet and spaces within the broader Reddit neurodiversity network, centred on community-driven written knowledge-sharing (Brownlow and O'Dell, 2006). By contrast, TikTok's short video format has enabled autistic and ADHD creators to present their own experiences, symptoms and identities in brief, emotionally resonant clips reaching audiences in the tens of millions (Gilmore et al., 2023; Aragon-Guevara et al., 2023; Leveille, 2024; McMillan, 2025; Alper et al., 2023).

This content diverges from traditional medical or educational portrayals in several important respects. It is first person rather than third person; it foregrounds adult rather than solely childhood experience; and it is frequently created by women, people of colour and LGBTQ+ individuals whose presentations remain under-represented in clinical literature (Gilmore et al., 2023; Leveille, 2024; McMillan, 2025; Alper et al., 2023). TikTok's algorithmic recommendation systems distribute such material to users whose engagement patterns suggest potential relevance, functioning as an unintended yet structurally significant informal screening mechanism for neurodivergent traits (Aragon-Guevara et al., 2023; Leveille, 2024; McMillan, 2025; Alper et al., 2023).

This paper adopts a systematic narrative review methodology (Popay et al., 2006), which is well suited to synthesising an emerging, heterogeneous body of work spanning multiple disciplines and methods. Systematic narrative review combines the procedural rigour of systematic searching with the interpretive

depth of narrative synthesis, supporting the identification of patterns, tensions and gaps across a developing evidence base (Popay et al., 2006; Barnett-Page and Thomas, 2009).

A comprehensive search was undertaken across PsycINFO, MEDLINE, Scopus, Web of Science and Google Scholar. Search terms combined "autism", "autistic" or "ASD" and "ADHD" with "social media", "TikTok", "Instagram" or "YouTube", and with "self-diagnosis", "self-identification", "late diagnosis" or "adult diagnosis". Additional searches targeted combinations of "neurodiversity", "social media", "identity", and "diagnostic delay" with "neurodevelopmental". The search was limited to publications from January 2015 to March 2026, aligning with the period during which adult, social media mediated recognition of neurodivergent identity has been documented. Although no language restrictions were imposed, only English language sources were ultimately included, reflecting the paper's UK policy focus.

Studies were eligible if they: (a) examined the role of social media in autism or ADHD identity recognition, self-diagnosis or community formation among adults; (b) investigated late diagnosis or diagnostic delay in autism or ADHD; (c) addressed equity dimensions of neurodevelopmental diagnosis; or (d) assessed the accuracy or reliability of social media based autism or ADHD content (Aragon-Guevara et al., 2023; Gilmore et al., 2023; Leveille, 2024; McMillan, 2025; Alper et al., 2023). Studies were excluded if they focused exclusively on children, on clinical populations without reference to social media, or on unrelated neurodevelopmental conditions.

Guided by established narrative synthesis procedures (Barnett-Page and Thomas, 2009), included studies were organised thematically into four areas of tension, which structure the findings section. Within each theme, convergent and divergent findings are presented and interpreted through the conceptual lenses of the neurodiversity paradigm and identity theory.

#### **4. Findings: Four Key Tensions**

### **Tension 1: Epistemic Legitimacy vs Clinical Accuracy**

Debate continues over whether social media self-identification is a legitimate pathway to recognising neurodivergent identity or primarily a vehicle for misinformation driven self misdiagnosis (Yeung et al., 2022; Botha et al., 2021). Evidence on the accuracy of autism and ADHD content online is mixed: some work on TikTok and other platforms suggests that lay and clinical audiences can find substantial portions of autism related content consistent with clinical understandings, though accuracy varies by format and creator, whereas studies of ADHD TikTok content report high rates of misleading or oversimplified material, especially from creators without ADHD (Yeung et al., 2022). Neurodiversity scholars argue that “accuracy” judged solely against existing diagnostic criteria is problematic because those criteria were developed through historically narrow, non participatory research focused on white, male, childhood cohorts, and may capture only part of autistic and ADHD lived experience (Botha and Gillespie Lynch, 2022). This exposes a core epistemic tension between clinical authority grounded in standardised criteria and community authority grounded in shared lived experience, each with its own legitimacy (Botha, 2020; Botha et al., 2021).

### **Tension 2: Community Affirmation vs Misinformation**

Online autistic and ADHD communities are associated with stronger autistic identity, higher well-being, and a greater sense of belonging for many participants (Botha, 2020; Botha et al., 2021). For late identified adults, these spaces may offer first experiences of recognition and validation (Botha and Gillespie Lynch, 2022). Simultaneously, concerns persist that formats such as “TikTok ADHD” foreground highly relatable, aestheticised traits and underplay the severity of executive dysfunction and impairment, potentially distorting public understanding (Yeung et al., 2022). Policymakers and platforms therefore face the dilemma that the same algorithmic and

social dynamics that amplify misinformation also spread accurate, affirming and practically useful content (Yeung, 2025). Restrictive interventions risk harming communities that rely on these spaces for support.

### **Tension 3: Empowerment vs Exploitation**

The commercialisation of neurodiversity content has created opportunities for autistic community connectedness and identity-affirming culture, but also for exploitation, as large audiences attract monetisation by both neurodivergent and non-neurodivergent creators (Botha et al., 2021; Botha and Gillespie-Lynch, 2022). Similar tensions arise around online ADHD assessment and prescribing services; while investigative journalism has raised concerns about rushed, low rigour assessments and rapid prescribing, these services have also enabled faster access to diagnosis and treatment for adults facing prolonged public sector waits. The ethical balance between access, quality and commercial incentives remains unresolved.

### **Tension 4: Digital Access vs Diagnostic Inequity**

Social media-mediated self-identification depends on stable digital access, platform literacy, and participation in spaces where neurodiversity discourse circulates, resources that are unevenly distributed across socioeconomic status, age, race, and disability (Botha and Gillespie Lynch, 2022). Autistic adults from marginalised racial/ethnic groups and those with higher support needs are less likely to benefit from online community connectedness, despite facing greater structural barriers to formal diagnosis and care (Botha, 2020; Botha et al., 2021). As a result, social media functions as a partial, inequitably distributed workaround rather than an adequate response to systemic diagnostic failures.

## **5. Discussion**

### **5.1 Social Media as a Diagnostic Mirror**

The emergence of social media-mediated self-identification highlights critical shortcomings within formal diagnostic systems. The phenomenon of hundreds of thousands of adults recognising themselves in TikTok videos prior

to clinical assessment indicates a healthcare issue rather than a problem inherent to social media. In this context, social media functions as a diagnostic mirror for populations overlooked by formal systems.

This understanding reframes the policy question. Rather than focusing on suppressing or correcting social media-based self-identification, it is more productive to investigate why so many adults find in brief online content what formal clinical contact has failed to provide, and how formal systems might adapt in response.

### 5.2 Implications for NHS Policy

NHS England's forthcoming neurodevelopmental strategy should address social media-mediated self-identification as a structural phenomenon rather than solely a patient behaviour issue. This approach includes investment in community-based diagnostic pathways that minimise waiting times, formal partnerships with autistic and ADHD community organisations to develop culturally and demographically inclusive assessment frameworks, and the integration of self-identification as a legitimate starting point for clinical assessment rather than a substitute.

### 5.3 Implications for Platform Governance

Social media platforms have an emerging responsibility that is not yet fully addressed within their governance frameworks. As platforms increasingly mediate the recognition of neurodevelopmental identity for millions of users, they share responsibility for ensuring the quality, accuracy, and equity of this process. While this does not necessarily require content moderation, which may risk suppression and discrimination, it could involve partnerships with autistic community organisations to enhance content quality, algorithmic design that promotes diverse and accurate neurodiversity content, and transparency regarding the commercial incentives influencing neurodiversity-related content recommendations.

### 5.4 Implications for Clinical Practice

Clinicians in primary care, mental health, and specialist neurodevelopmental services are increasingly encountering patients presenting with social media-informed self-identification. Current clinical frameworks frequently regard this as a challenge to be managed. A more constructive approach would consider social media self-identification as clinically relevant information, representing the patient's interpretation of their experience and warranting exploration rather than dismissal.

## 6. Conclusion

Social media-mediated self-identification of autism and ADHD constitutes a significant and underexamined intersection of digital culture, neurodevelopmental health, and health equity in contemporary UK society. This phenomenon warrants serious consideration and analytical rigour.

This review contends that social media self-identification should be understood as a rational, community-generated response to systemic diagnostic failure, with tangible benefits and risks unequally distributed across the population. Neither uncritical celebration nor outright condemnation is sufficient. An effective policy response must engage individuals within online communities and digital environments, while simultaneously strengthening formal diagnostic systems.

Future research should prioritise longitudinal studies of self-identified adults who subsequently access formal assessment; participatory research that co-produces knowledge with autistic and ADHD communities about the role of online self-identification in their lives; and equity-focused analyses of who is and is not reached by social media-mediated recognition of neurodivergent identity.

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