

## **Transnational autistic identities: Disrupting ghost authorship with digital discourse.**

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### **Abstract.**

*What autism provided was a discursive framework, a lens through which others could story my life...[t]his, my body, this was autism—and suddenly, with the neuropsychologist’s signature on my diagnostic papers, I was no longer my body’s author. (Yergeau, 2018: p. 11)*

### **Introduction**

In *Authoring Autism: On Rhetoric and Neurological Queerness* (2018), Melanie Yergeau describes the damage of prevailing autism discourse when she is diagnosed with Autism Spectrum Disorder (ASD) as a young adult. As soon as she receives the autism label from a neuropsychologist, she begins to experience a dispossession of agency and authorship of her own identity, a phenomenon that can be called ghost authorship. She portrays the label of autism as an act of violence upon her body and ways of knowing. She writes:

*My hand and full-body movements became self-stimulatory behaviors; my years-long obsession with maps and the Electric Light Orchestra became perseverations; my repetition of lines from the movie Airplane! became echolalia. My very being became a story, a text in dire need of professional analysis. (Yergeau, 2018: p. 11)*

Although she had always moved, communicated, and interacted with the world in these ways, the ascription of an ASD label by another—a neuropsychological professional, an “expert”—was taken as a seminal endorsement for other interlocutors to attribute Yergeau’s characteristics and life stories to autism without her participation or permission. As she ascertains throughout her book, this kind of experience is curated by outsider narratives of autism, which include the work of parents, professionals and scholars. These perspectives, which are steeped in pathology and stigma, are often society’s first and only encounter with ASD or people who identify as autistic (Mann, 2018). As such, once a person is labeled “autistic,” outsiders read the autistic body as a list of diagnostic criteria (Yergeau, 2018).

Privileging the scholarship and creative work of autistic<sup>1</sup> people has the potential to disrupt the neurotypical dominance deeply established in autism narratives and research. In the last decade, the scope of autism narratives has expanded to include more first-person accounts authored by increasingly diverse autistic identities. Memoirs and autobiographical books have contributed valuable perspectives regarding neurodiversity and impairment in multicultural and multiracial spaces, especially for people of color. Many of these authors' works provide important insight regarding critical issues in disability, such as access to meaningful communication and racism in the United States (Mukhopadhyay, 2000; Prahlad, 2017). Other notable developments include the work of women and LGBTQQIP2SAA<sup>2</sup> individuals who claim autistic and/or neuroqueer identities (Brown, 2018; Brown et al., 2017; Yergeau, 2018). These works center experiences which have generally been absent from autism narrative and scholarly canons since Kanner and Asperger published their seminal texts in the 1940s<sup>3</sup>.

Despite the nascent diversity in autism discourse, there is a dearth of scholarship focused on the experiences of transnational, multilingual and/or multiply disabled autistic individuals. The underrepresentation of these populations in autism research and publications has negative implications for issues regarding support, inclusion, visibility and access to services for autistic people. Further, this underrepresentation could contribute to the dispossession of agency over identity, body and space experienced by people like Yergeau.

Autistic identity is represented or studied as separate from multilingual or transnational identity. This is evidenced by scholarship bridging language- and disability-related education labels and access to supports and services in U.S. schools. In these contexts, students assigned (im)migrant or refugee status are often read as either English learners *or* students with disabilities (Kangas, 2014). This impacts access to culturally sustaining education experiences, such as bilingual education (*ibid.*). Scholarship focused on the interactions between language, culture and identity overlooks the contributions of autistic individuals and groups, instead situating multilingual and/or multicultural autistics solely within studies of inequity (Estrem and Zhang, 2010; Lim et al., 2018). This limitation affects the control and status of knowledge afforded to (and by) autistic people—especially those living transnational lives, which often involves communicating and accessing cultural knowledge across political, social or linguistic borders.

The following discussion illustrates the need for scholarship focused on transnational autistic experiences through culturally responsive research practices. First, I provide a brief literature review of scholarship regarding transnational identity, autism and online communities to illustrate the relationships between and among these concepts. I conclude that studying these relationships could provide foundational understanding of autistic knowledge and identity that is non-white, multilingual and representative of the experiences of various individuals marginalized due to ability, cultural and linguistic differences.

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<sup>1</sup> There is much debate in autism communities regarding the use of identity-first or person-first language. While many parents, advocates and professionals support the use of person-first language, many autistic individuals emphasize the use of identity-first language (Brown, 2011; Kenny et al., 2016; Sibley, K., 2018). The author uses identity-first language throughout the text to reflect the preferences of individuals who identify as autistic, rather than individuals who do not claim this identity.

<sup>2</sup> LGBTQQIP2SAA is an acronym which includes Lesbian, Gay, Bisexual, Trans, Queer, Questioning, Intersex, Pansexual, Two Spirit, Asexual, and Ally (Lorenc, 2016).

<sup>3</sup> Although the term “autism” and variations had already been coined by psychiatrists such as Eugen Bleuler in the early 1900s, the works of Kanner and Asperger are largely the foci of public and literary interest in the historical development of autism and the autism narrative (Donovan & Zucker, 2016; Silberman, 2015).

I then demonstrate the potential for digital discourse analysis in transnational autistic communities through a case study of a selected group of message board users. I identify conversation analysis (CA) and systemic functional linguistics (SFL) as instrumental approaches to autism research that could center the knowledge and experience of autistic individuals in research. Because blogs, message boards and other online platforms have supported a renaissance of autistic identity construction and expression, CA and SFL could serve as important tools to document and analyze communal and individual expressions of identity, history and culture. Finally, I suggest future directions for research. I conclude that scholars who are white and native English-speaking from western nations should consider digital discourse analysis as one way that they might use their cultural and academic assets to privilege the work and knowledge of more diverse autistic individuals and communities.

### **Transnationalism, online communities and autism**

Transnationalism is understood as operation across national or political borders. More specifically, transnationalism “recognizes the significance of national frameworks alongside the potential of cultural production both to reinforce and to transcend them” (Rigney and De Cesari, 2014: p. 4). In understanding identity, it is important to understand the difference between “transnational” and “international.” The prefix “trans” invokes a sense of embodiment or carrying across innumerable nations (or innumerable crossings), as opposed to “inter,” which indicates a finite duality between nations and crossings. Recent scholarship presents transnationalism as a recursive practice of individuals and cultural, linguistic and ethnic communities. For example, Christiansen (2017) analyzed the connection of temporal and spatial relationships by transnational Mexicans, which resulted in the construction of a single context. Using a discourse-centered ethnographic approach, Christiansen analyzed the ways participants used Facebook communication structures to express and maintain culture and language across political boundaries (*ibid.*). This study provides an example of how digital communities like Facebook, where users synchronously and asynchronously<sup>4</sup> (co)construct and maintain identities, give deeper insight into the meanings and processes of cultural knowledges.

Transnationalism as a constructive practice has critical implications on autistic identity development, since autism and other disability labels are ascribed, treated and experienced differently worldwide. Very few discourses of disability and identity embrace related issues across political borders. For example, in *The Right to Maim*, Puar (2017) explores how transnational biopolitics interact with shared understandings of disability and oppression, but she objects to the idea of “disability” as an individual cultural identity (*ibid.*). Further, despite widespread adoption of international disability policy, such as the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) (Soldatic & Grech, 2014), there are some countries that do not adopt a human rights approach to disability-related issues. These countries, like the United States, seem to take an ad hoc approach to disability policies regarding physical accessibility, social programs and education, in reaction to socio-political change (Hunt, 2011). This means that an individual living transnationally through immigration, migration or other circumstances might have different experiences with or because of perceptions of their disability across contexts.

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<sup>4</sup> *Synchronous* refers to communications or interactions that take place at the same time and in the same space, or in real time. *Asynchronous* refers to communications or interactions that take place in the same space, but at different times.

Transnational life, unlike life in one country, has a unique influence on an individual's identity and relationships. Transnational life also fosters unique cultural and political identities for groups, especially in the wake of settler colonialism (Simpson, 2014). Petró and Greybeck (2014) studied how transnational ways of knowing presented at the forefront of the cultural and linguistic practices of a group of educators. Participants utilized recursive interactions with ancestral languages, native language, and ancestral and contemporary spaces to construct a new multilingual heritage (*ibid.*). In the United Kingdom, Hua and Wei (2016) focused on the complex, community-based structures of meaning regarding bilingualism versus multilingualism in transnational families. Although these works offer new perspectives on transnationalism and its embodiment within/through language, there is no discussion of the implications of disability or neurodiversity. For example, in U.S. schools, autistic (im)migrant students have limited access to their native or heritage languages in public schools. In fact, the benefits of integrating native or heritage languages into autistic students' therapies is still questioned (Lim et al., 2018). As such, the emphasis of language in scholarship of transnational communities could challenge the conceptualization of autistic (im)migrant students as monolingual or ambiguously multilingual.

Online communities play an integral role in understanding and centering autistic and/or transnational identities. For transnational individuals and groups, online communities and digital discourse often serve as the primary media for cultivating knowledge and language. In addition to the work of Christiansen (2017), Black (2009) analyzed the transnational interactions of three English learners who used language and other representational sources to maintain social relationships across political borders and to learn English through experimentation with unfamiliar genres and composition formats. Bickel et al. (2013) studied the personal communications and academic work of a group of Brazilian English learners participating in an online course offered by educators in the U.S. The authors found that meaningful learning outcomes, such as critical self-reflection, collaboration and civic engagement was largely inspired by the students' aspirations to cultivate transnational social networks through online course communication and other social media. These students were able to engage in more effective learning because of their exposure to and sustained interest in transnational digital spaces (*ibid.*). These findings highlight the potential for transnational digital platforms to provide new or deeper knowledge of autistic life and relationships than those spaces that have already been explored.

In scholarship focused on autism, online communities frequently emerge as preferred social networking and personal expression platforms. In challenging assumptions about the purpose and effects of therapeutic interventions like Applied Behavior Analysis (ABA), Brownlow (2010) turned to online communities for autistic adults as well as parents of autistic individuals. Brownlow found that online communities for parents focused on therapy, whereas digital spaces created by autistic people focused on conceptualizing normality and abnormality, rejecting change, and implications for employment (2010). Missing from this work is the intersection of race, language and other markers that impact the inclusion and post-secondary school outcomes for autistic adults. Later, Gillespie-Lynch et al. (2014) used a self-reported survey to compare the Internet use of autistic and non-autistic individuals. They found that people who identified as autistic were more likely to use the Internet to express their chosen identities and meet people with shared interests. This study, although missing discussions of race and language, illustrates the importance of online communities in understanding first-person narratives and discourse about autism.

Well-established bodies of research focused on transnationalism, autism and online communities' discourse provide isolated foundational perspectives of related identities and practices, especially in emergent research focused on transnational or autistic cultural identity construction through digital media

and communities. This highlights a significant gap in scholarship documenting the identities of transnational individuals or autistic groups using digital discourse communities. Transnational autistic discourse communities could expand our understanding of autistic knowledge and identity that is non-white, multilingual and representative of the experiences of multiply-marginalized individuals. As evidenced by research and first-person narratives, online spaces support communication and expression across social and political barriers in ways that do not necessarily re-center the perspectives of white, non-autistic interlocutors. Scholars seeking to disrupt the white uniformity of autism research might consider learning from the culture and language practiced in transnational, digital discourse communities.

### **Analytical framework**

When analyzing online communities, Brownlow claimed that discourse analysis promoted “moving beyond perceiving language as a tool for communication to viewing language as actively constructing what is understood” (2010: p. 16). This view of language is a common principle of discourse analysis, wherein language is central to knowledge construction. In studying transnational autistic discourse communities online, there are two kinds of discourse analysis that facilitate the investigation of digital discourse as a medium for synchronous and asynchronous collaboration. The first, critical conversation analysis (CA), could be instrumental in differentiating between ameliorative and pejorative connotations associated with variations of the words *autism* and *autistic* through asynchronous conversations. The second, systemic functional linguistics (SFL), might provide an analytical framework for learning about generalized autism-related discourse among autistic and non-autistic individuals within the same transnational communities. Both approaches could draw attention to the ways autistic identities are constructed and negotiated in dynamic digital spaces.

### ***Conversation Analysis***

Clayman and Gill describe CA as an approach to understanding “the institution of interaction, norms of interactional conduct, and the methods of reasoning implicated in the production and recognition of action” (Clayman and Gill, 2012: p. 120). CA is largely used to analyze spoken communication, but Clayman and Gill claim that it might potentially serve in similar communicative contexts, like those in digital spaces. Although they are traditionally considered to be asynchronous communications, online conversations and interactions on sites like Reddit<sup>5</sup> and 4chan<sup>6</sup> function in many of the same ways as synchronous communication. This association is validated by Clayman and Gill’s discussion of sampling. They write,

*Unlike many fields, CA addresses a domain of phenomena whose components are not yet fully known or understood... Because the objective of CA is to describe the endogenous organization of interactional phenomena rather than to determine their distribution, the issue of sampling is approached rather differently here from other fields. (2012: pp. 121-122)*

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<sup>5</sup> Reddit.com is a social news, content sharing, discussion and blogging website. Users can access, create, share and rate content, as well as participate in discussion threads on various thematic message boards.

<sup>6</sup> 4chan.org is an anonymous message and image board website where users create and respond to content on various thematic message boards.

This means that digital discourse, though not always synchronous, could qualify for conversation analysis. Clayman and Gill instruct scholars to “begin with relatively unmotivated observation... a bit of conduct that seems in some way ‘interesting’” (2012: p. 124). This approach is optimal for discussion threads, message boards and blog sites, which often contain hyperlinks, “re-blogs<sup>7</sup>,” and other asynchronous tangents to follow targeted ideas and language use. Further, digital discourse in these spaces often shares the same characteristics as real-time communication, including recursive structures, simultaneous exchanges and utterances, minimal responses, and even textual descriptions of laughter and gesticulation.

### *Systemic Functional Linguistics*

While CA serves analysis of word forms and connotations, SFL might serve analysis of digital discourse in a larger social context. Schleppegrell (2012) describes SFL as an approach to “exploring meaning in language and of relating language use to social contexts so as to contribute to our understanding of language in social life” (2012: p. 21). SFL can therefore illuminate the role of language in autistic identity construction in digital communities navigated by autistic and non-autistic individuals. That is, how do community members implement autism discourse when they claim an autistic identity as opposed to when they receive an autism diagnosis? How do community members implement this discourse when they are not autistic? Further, SFL can help scholars address the ways autism is constructed by autistic and non-autistic individuals.

SFL is beneficial for use in analyzing digital discourse because of its emphasis on text-based sampling. Unlike other forms of discourse analysis, SFL is based on the cohesive nature of text-based communication, including reference, substitution, ellipsis and other ways text may “hang together” (Schleppegrell, 2012: p. 24). These and numerous other text features are found within digital discourse. Further, ideation analysis, which is a kind of SFL, has been used in previous scholarship to study agency in experiential reconciliation between ethnic groups (Martin, 2006: p. 292, as cited by Schleppegrell, 2012: pp. 25-26). Other applications of SFL include discourse in foreign language classrooms, social studies textbooks and clinical contexts (Schleppegrell, 2012).

Although CA and SFL can be implemented to answer different kinds of questions in different digital spaces, both could be used to analyze aspects of communal and individual expressions of identity, history, and culture. CA serves word-level analysis best, since this type of analysis begins with noticing discrete patterns of language use. Studying the morphology of “autism” and its forms could lead to a more general analysis of *how* and *why* those forms exist, especially in digital discourse communities where morphologic variations are created and used for specific purposes for different groups. Multimedia memes, which are popular on (and often derived from) sites like Reddit, 4chan and Tumblr, are examples of this phenomenon.

At the syntactic level, researchers could see how autism discourse is applied or appropriated at the sentence level. This is important, because some online communication is asynchronous. In these cases, “utterances” can consist of a sentence or phrase at a time—or entire blog compositions. SFL can be

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<sup>7</sup> “Re-blogs” and “re-blogging” refer to online community or platform users re-posting or featuring content from their own profiles or blogs, or from the profiles and blogs of other users. This term is regularly used on sites like Tumblr.com.

implemented in analyzing systemic-level discourse, especially to understand differences between groups that utilize separate or integrated digital spaces.

### Case Study: Agency and Authorship Online

Authorship of autism is rich in differences and discourse in digital spaces like Reddit. Within this platform, users from around the world engage in mostly asynchronous discussion threads to address user-generated questions and moderator-selected themes or discursive styles. One such thread is the r/IamA subreddit<sup>8</sup>, which invites users to declare an identity, then field questions from other users about that experience (u/hell0h1, 2019). The rules for this thread are specific: interlocutors who did not begin a new thread by declaring an identity can only post questions to the focus user. This centers the initiating Reddit user as the source of knowledge while allowing that user uninterrupted agency and discursive power.

In this segment of the r/IamA subreddit, a Reddit user named u/hell0h1 started a discussion thread with the following:

*IAmA Half-Japanese 19M with Asperger's (Autism and ADD) and I recently moved to the states. AMA!*

*I've lived in various parts of the world because my dad is Navy, but most of my life has been spent in Kanagawa, Japan. I used to be heavily autistic but learned to grow out of it at about age 12. I'm here to clarify any questions and maybe dispel some myths anyone may have about Japan or being Japanese or living with autism. (u/hell0h1, 2019)*

In this initiation, u/hell0h1 showed how disability, culture, and transnationalism shaped his identity. Although he has lived a transnational life, he presents his national and cultural identity as Japanese and positions himself as an authority for others on this topic. He also presents himself as a gatekeeper to autistic cultural knowledge, inviting the opportunity for outsiders to question and “dispel some myths” about “living with autism” or “being Japanese” (*ibid.*)

Further exploration of this thread reveals examples of autistic users comforting others and negotiating the conceptualization of diagnosis in a way familiar to Yergeau in *Authoring Autism* (2018). As seen in his initial post, u/hell0h1 claims a disabled identity, presenting himself as having an Asperger's label. He then deconstructs that label, explaining in parentheses that he perceives that to subsume “Autism and ADD.” He also explains that he was “heavily autistic” as a young child but “learned to grow out of it” as he aged. In so doing, u/hell0h1 seems to promote a recovery narrative which constructs him as reformed or as an experienced survivor of the experience. Later the conversation, u/hell0h1 offers assurance to another user who expressed hesitation about seeking a professional diagnosis for ASD. He writes:

*What is there to be worried about? [...] If you wanted to go get tested, then that's up to you. Even if you test positive for autism, it doesn't really change anything. You didn't*

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<sup>8</sup> A subreddit is a thematic blogging and discussion thread page on Reddit.

*suddenly become autistic because of the test; you've lived with it your whole life without knowing and by 22 you've already likely learned to live with it.* (u/hell0h1, 2019)

This assertion that the hesitant user would not “suddenly become autistic because of the test” connects to Yergeau’s (2018) experience of dispossession upon receiving her own autism diagnosis as an adult, wherein she did suddenly “become autistic” to others once she was identified as such by a neuropsychological professional. In her book, she also shares the experience of living as an autistic person “without knowing,” which u/hell0h1 articulates in this post. In this example, Yergeau’s seemingly insular experience reemerges as a common cultural experience of autistic individuals across contexts.

Beyond this example, there are a variety of rich and sometimes intimate discussions on Reddit which can reveal more about what it means to claim and articulate an autistic identity across borders. One former Reddit user from a transnational background, u/Kidpolly, participated in a thread for autistic and non-autistic users in the r/autism subreddit to deconstruct issues around humor and autism. As the discussion unfolded, autistic users negotiated differences between claiming autistic identity markers as self-deprecation or as disability pride. In one post, a following user, u/\_STLICTX\_, grappled with the conditions of ableist language in many jokes, saying, “[It] depends on the joke? Jokes that imply being autistic makes you inferior like most do I don't like because I don't like the underlying implication autistics are inferior.” Non-autistic users simultaneously participated in this and other discussions with autistic users regarding the appropriation of disability as humor and apology (u/gRowlxd, 2018). Discourse analysis of this discussion thread alone could reveal much about current issues in self-advocacy, outsider perceptions, and pride in a multicultural, heterogenous space.

## Considerations

Careful observation and consideration of online communities is crucial when studying digital discourse in ways that are different from other empirical contexts. For example, because online communities are continuously created, adapted and occupied in various ways, real-time trends in language use are often difficult to capture as they develop. Additionally, online communities afford users certain degrees of anonymity. Publicly available user content might help scholars circumvent the (often restrictive) authority of institutional review boards, which often limit the participation and study of individuals with disabilities and other social groups deemed vulnerable. However, collecting language data from anonymous users comes with its own risk: researchers cannot always be sure that users are who they say they are. Although this potentially affects the reliability of data and analysis, it is a risk that is difficult to entangle from this kind of research.

Nonetheless, there are innumerable online communities where scholars can engage transnational autistic individuals and groups. Many sites, such as Wrongplanet.net<sup>9</sup>, Reddit, and Tumblr feature blogs and user profiles as well as discussion threads. Engagement with these interfaces is likely best supported by CA, since the use of hyperlinks and “re-blogging” functions facilitate the tracing of specific words or semantic pairs.

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<sup>9</sup> Wrongplanet.net is an online blogging and message board community primarily accessed and mediated by users who are autistic or self-identify using labels associated with the ASD spectrum.

## Conclusion: The need for digital discourse analysis

This paper began with an intimate description of the experience of dispossession—the violation of agency over body, mind and experience by outsider ascription of autistic identity. Yergeau writes about how the assignment of an autistic label seemed to change even interlocutors’ historicizing of her body and personality after discovering the diagnostic criteria for ASD. Yergeau’s experience of dispossession by outsiders’ perspectives of autism is the result of the power non-autistic/neurotypical outsiders have over language and perceptions regarding ASD but it is not a singular experience, as evidenced by u/hell0h1’s performance of agency and authorship in his interactions with other Reddit users. Because the knowledge and narratives promoted by outsiders is predominantly white, cis male and English-speaking, other autistic knowledge is diminished to minoritized status. Perhaps these transnational autistic individuals are so often ignored in existing research practices because, like Yergeau’s narrative, they seem to represent singular or isolated experiences which do not yield dramatic, global significance like large-scale data.

Scholars who are white, native English-speaking and from western nations need to consider how their cultural and academic assets could be used to privilege the perspective of more diverse autistic individuals and communities. This work is already being done on an unrecognized scale in digital spaces by individuals like u/hell0h1, who practice agency and authorship in producing transnational autistic knowledge to provide support for their peers. Existing research regarding autism within the context of race and/or settler colonialism is often primarily authored by white and/or non-autistic scholars (Lecluijze et al. 2015; Savarese, 2010). Digital discourse analysis of transnational autistic spaces can shift the attention from *autism* experts to *autistic* experts, and could create culturally relevant spaces for co-authorship and co-scholarship between and among these groups.

Online communities are generally accessible to individuals and groups across ability levels and political borders. Although digital discourse in spaces like Reddit might be an untapped resource for autistic knowledge, experience and culture, existing approaches to discourse analysis like conversation analysis and systemic functional linguistics can be adapted to study them. However, the raced, gendered and linguistic conflicts concerning autistic perspectives, or the omission of these perspectives, cannot be mitigated or resolved through innovative research in isolation. Unless scholars, authors and other outsiders are privileging marginalized forms of autistic knowledge, we will never be able to disrupt the enduring ghost authorship of autism.

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