Examining Neurodivergent Wikimedian Experiences: A Content Analysis and Investigation into Demographic Research Methods

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Abstract

We are presenting our in-progress research to solicit community feedback. First, we are conducting a content analysis of existing public discussions about being neurodivergent and participating in Wikimedia projects, to investigate present discourse and scope this novel research area. Second, we are creating a public report recommending methodological considerations for further research on neurodivergent Wikimedians, given the complexity and the lack of existing studies about how to ethically study this complex demographic. The potential impact of this work is to increase understanding of how to support Wikimedian wellbeing, and to prepare the community for future inquiry to understand the representation of neurodivergent Wikimedians.

Keywords: Neurodivergence, Neurodiversity, Research Methods, Demographic Research, Qualitative Research

Introduction

"Obviously Wikipedia was written by people with Aspergers," said Noah Britton, a member of the comedy troupe, Asperger's Are Us, in a live performance.[1] The idea that neurodivergent people are heavily represented among Wikimedia contributors is a trope within and outside Wikimedia communities. Yet the experiences of neurodivergent Wikimedians, as well as public discussions about this population, have not been the subject of scholarly research.

The terms *neurodivergent* and *neurodiversity* are concepts which address brain differences and challenge stigmas associated with diagnostic categories that pathologize brain differences as impairments. *Neurodiversity* has been used by disability activists and employed to recognize the social shaping or social model of disability since the late 1990s (Dyck & Russell 2019). We take up a neurodiversity framework to situate our research within these contexts, which focus on acceptance and building alliances across disabilities and combinations of difference, in contrast to medicalization (Gillespie-Lynch et al. 2020). However, there is a lack of precedent for how to mobilize the term neurodivergent in demographic research of sociotechnical communities. Hence, our research also involves methodological investigations we plan to present for feedback and peer-review.

We are presenting on in-progress research, with an official start date of 01 June, 2024. In Part 1 of our work, we are investigating the question: *what topics are discussed in existing public conversations about being neurodivergent and participating in Wikimedia projects?* Anyone interested in understanding the makeup of the Wikimedia community and supporting contributors, including organizers and technical support might be interested in this work. This work may also contribute to our understanding of neurodivergent people's experiences in work and volunteering contexts, as well as to our understanding of how to study this demographic in online contexts. Part 2 of our work involves producing a set of research design recommendations for future research on neurodivergent Wikimedians to present potential risks and ways to involve the community in shaping research and representing themselves.

Methods Discussion

Part 1: Content Analysis

Based on preliminary work to scope the feasibility of this study, we found 20+ discussions in English Wikimedia projects about being neurodivergent and contributing to

[1] Episode 3, *On Tour with Asperger's Are Us,* HBO, 2019.

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Wikimedia projects in public forums. For Part 1, a content analysis of existing discussions in English about participating in Wikimedia and being neurodivergent, 2001-2024 is being conducted.

Content analysis is a qualitative method to study discourse involving the creation of a corpus, followed by qualitative coding (Krippendorff 2018). Content analysis is an established qualitative methodology for surveying what a community has published about itself, to analyze existing public discourse. A corpus is being created by querying pages across English Wikimedia platforms, including essays, talk pages, user pages, and policies. Due to many forms of interaction on Wikimedia platforms, threaded discussions, user boxes and categories are all content formats that may be included in the corpus. We are keeping/reporting a log of search terms in data collection. We are querying all Wikimedia projects, but contextual data on data items is also being collected, such as the nature of surrounding talk page discussions and threads. Contextual data is important to understand Wikimedians on their own terms in forums where community issues are discussed and the nature of the forums that data items are gathered from.

The authors are using grounded theory for the analysis of the corpus, which involves creating qualitative codes based on keyword usage, subjects discussed, framings, and other emergent properties in the corpus, and labeling data items with these codes (Clarke 2005). Then, researchers synthesize underlying patterns.

We will interpret the results with care towards intersectional forms of marginalization and biasing that may appear in myriad ways at any point in the research process. Given the subject area, we will look out for comments that relate to concerns about stigma, masking, camouflaging, and the disclosure and non-disclosure of neurodiversity-related identity characteristics and diagnoses (Davidson & Henderson 2010), and how these might impact Wikimedia community awareness of the experiences and representation of neurodivergent contributors.

To protect the privacy of the authors of the public textual data analyzed, we will not use direct quotations or usernames in publications, and will paraphrase any quotes. Researchers also will develop a process for including texts originating from potentially sensitive contexts in our dataset, beginning with identifying indicators of sensitive contexts, such as discussions done in time-critical contexts, or indicators of excited states or states of distress. Authors will exclude items not clearly intended for public audiences.

Part 2: Research design recommendations for future research on neurodivergent Wikimedians

In Part 2, we will create a set of research design recommendations for future research on neurodivergent Wikimedians, given that studying demographic groups requires careful bias and risk considerations. Moreover, members of the population studied, including those with cognitive disabilities, may be classified as a vulnerable population by ethics boards, requiring further care and ethical awareness. We intend to explore ways to involve the community in representing themselves, and present our work at Wikimania 2024 and other community forums to gather feedback about potential risks.

We will document difficulties in applying the term neurodivergence in research contexts, given diagnoses and access to medicine, legal definitions, and protections of disability status differ internationally. Diagnoses that are commonly referenced as part of the neurodiversity category include autism, ADHD, dyslexia, OCD, dissociative disorders, personality disorders, anxiety, and other brain disorders, behavioral disorders, personality disorders, and mood disorders (Armstrong 2011). While the term neurodivergence implies inclusivity across brain differences, it is also necessary for researchers of neurodivergent populations to define criteria of inclusion in the category for the purposes of data collection.

Existing methods for studying demographic groups of Wikimedians are numerous. The international character of Wikimedians presents challenges and opportunities for those undertaking demographic research. We will explore methods for conducting demographic research about neurodivergent Wikimedians across multiple language Wikimedia-s in Part 2. The WMF has invested significant resources in producing a number of editor surveys. However, previous WMF surveys have not included questions about psychological wellbeing, disability status, or neurodivergence. The WMF has access to community messaging tools to conduct surveys in multiple languages that independent researchers lack. We will probe how our research on demographic research methods might inform future WMF editor survey design or future iterations of the Knowledge Gaps Index to identify ways to reduce barriers to entry and design for the accessibility, for neurodivergent people, a population with overlap in populations with disabilities.

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