Investigating Neurodivergent Wikimedian Experiences

Dorothy Howard
Wikimedia LGBT+

Lane Rasberry
University of Virginia,
School of Data Science

Steve Silberman
Author, stevesilberman.com

Abstract

This project will focus on exploring discussions about being neurodivergent and participating in Wikimedia projects. There are no existing studies on neurodivergent Wikimedians, although there are numerous discussions about the representation of this population of contributors in public forums. In Part I, we will conduct a content analysis of such existing public discussions about neurodiverse Wikimedians to investigate present discourse and define a research area. 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 planning and risk considerations. The potential impact of this work is to increase understanding of how to support Wikimedian wellbeing, including through understanding the challenges faced by neurodivergent Wikimedians.

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 representation and experiences of neurodivergent Wikimedians 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; Krcek 2013). We take up a neurodiversity framework to situate our research within these contexts, which focus on empowerment, acceptance, and building alliances across disabilities and combinations of difference, in contrast to medicalization (Gillespie-Lynch et al. 2020).

This project investigates: *what topics are discussed in existing public conversations about being neurodivergent and participating in Wikimedia projects?* Given the absence of existing research on neurodivergent Wikimedians, despite the potential vastness of this demographic, this content analysis will inform the second part of this work, in which we will investigate: *what are important methodological considerations for the design of future studies on neurodivergent Wikimedians?* 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.

Date: June 1, 2024 – December 1, 2024.

Related work

Neurodiversity, Work, and Tech Work
Research on neurodivergent people at work may be applicable to understanding aspects of the social worlds of labor, collaboration, and knowledge production among this population, with research on neurodivergent people

---

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

working in the tech sector particularly applicable. Research on the obstacles faced by neurodiverse people on the job, such as bullying, stigmas, discrimination, and anxiety (Alm 2014; Botha & Frost 2020) may be applicable to this study. There is no data on how stigmas or discrimination might affect neurodivergent Wikimedians, although users have posted about related issues in public forums. In 2001, Steve Silberman published a *Wired* article, "The Geek Syndrome" about the convergence of people on the autism spectrum in computing careers in Silicon Valley. Silberman's article and subsequent book *NeuroTribes* (2015) raised questions about why people on the autism spectrum might succeed in the tech industry. Some papers have identified qualities associated with autistic individuals that overlap with the job demands of software development, such as "systemizing, information processing, specialization of interests" (Annabi et al. 2017) and "pattern recognition" (Armstrong 2010). Other work discusses obstacles faced by neurodivergent tech workers, like concerns around disclosure/non-disclosure of diagnoses, and workplace communication (Morris et al. 2015). This research on the challenges and opportunities faced by neurodiverse computing workers may be useful to apply to the context of Wikimedia contributors given the scope of technical work Wikimedians engage in. We have also identified a dearth of literature about neurodivergent people volunteering on and offline in unpaid contexts. Howard has experience researching labor in the social worlds of open source software.

Neurodivergence and Internet Culture
In a study of autobiographies by autistic people, Davidson suggests that there are "distinctive autistic styles of communication" and discusses how autistic peoples' preferences for text-based communication relates to Internet usage (2008). Davidson focuses on patterns across many first-person testimonials that emphasize how autistic people have flocked to online communities including chat rooms, email lists, and bulletin boards and created distinct autistic cultures online due to the affordances of digitally-mediated communication

(Price-Hughes 2004). Such research is highly applicable to this study in interpreting the cultures of interaction and communication that occur in Wikimedia communities among neurodivergent populations.

Studies of Wikimedian Demographics
Existing methods for studying demographic groups of Wikimedians will be consulted as we develop methods recommendations for studies on neurodivergent Wikimedians in Part II. The WMF has invested significant resources in producing a number of editor surveys and has access to community messaging tools to conduct surveys in multiple languages that independent researchers lack.[2] However, previous WMF surveys have not included questions about psychological wellbeing, disability status, or neurodivergence. Our research might inform future WMF editor survey design. Our research might also inform the WMF Research team's consideration of modes of including considerations of neurodiverse Wikimedians in future iterations of the Knowledge Gaps Index (Wikimedia Research, 2020) to identify ways to reduce barriers to entry and design for the accessibility, for neurodivergent people, a population with overlap in populations with cognitive, developmental, intellectual, mental, physical, and sensory disabilities.

Methods

PART 1: Content Analysis
A content analysis of existing discussions about participating in Wikimedia and being neurodivergent will be conducted. Content analysis is a qualitative method to study discourse involving the creation of a corpus, followed by qualitative coding (Krippendorff 2018).

A log of search terms to collect data will be reported. The corpus will be created by querying pages across English Wikimedia platforms, including essays, talk pages, user pages, and policies. Due to many forms of

---

[2] See: https://meta.wikimedia.org/wiki/Category:Editor_surveys

interaction on Wikimedia platforms, threaded discussions, user boxes and categories are all content formats that may be included in the corpus. Contextual data on data items will also be collected, such as the nature of surrounding discussions and media. This data will be important to understand Wikimedians on their own terms in forums where community issues are discussed. Data will be gathered from 2001 to June 2024 to account for the history of Wikimedia projects.

The authors intend to use 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 disclosure, non-disclosure and *masking* (Davidson & Henderson 2010), and how these might impact Wikimedia community awareness of the experiences and representation of neurodivergent contributors.

PART 2: Further Research Design on Neurodivergent Wikimedians

Part 2 will involve creating methods and methodological recommendations for future studies about neurodivergent Wikimedians. This component of the proposal is necessary because the novelty of this research area and the complexities of studying demographic groups, particularly those with potentially vulnerable populations, requires time and care spent investigating methods, potential bias and risks, and ways to involve the community in representing themselves. We will create actionable recommendations for future research design that might be useful for researchers and movement advocates designing future studies about neurodivergence in online communities.

As part of our methodological work, authors expect to 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 (Doyle 2020). 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.

Expected output

- An open-access research publication.
- A research report published on a Wikimedia page for a general audience.
- A public report with recommendations for future researchers.

Risks

This study does not include the participation of human research subjects. Risks include creating unwanted or negative public attention on the population studied. We plan to dialogue with the Wikimedia community and other researchers at Wikimania and other forums as this project develops, to expand our awareness of potential risks. To protect the privacy of the authors of the public textual data analyzed, we will not use direct quotations or usernames in related publications, and will paraphrase quotes if/when necessary. Researchers also commit to developing a process for including texts originating from potentially sensitive contexts in our dataset, beginning with identifying indicators of sensitive contexts, such as discussions on talk pages done in time-critical contexts, or indicators of excited states or states of distress. Such a set of indicators of sensitive contexts may be useful for other Wikimedia researchers. Any public data set created for this project would only include textual data sources designed with the public in mind, such as Wikipedia essays, rather than Talk page

messages or other internal, community-oriented discussions. Authors will exclude items not clearly intended for public audiences.

Community impact plan

We intend to dialogue with the Wikimedia community in which researchers are embedded to explore potential risks of this research. Our work will produce recommendations about how to operationalize our findings for both Wikimedia organizers and other researchers. We will also suggest areas for future work in our publications. Data on challenges faced by neurodivergent Wikipedians can inform strategic planning to improve community experience. This study could be a source for the production of a rights statement involving neurodivergent Wikimedians. Such a rights statement should involve neurodivergent Wikimedians in the creation process to increase community impact. The proposed work might inform those identifying ways to reduce Wikimedia's barriers to entry and accessibility. To share our findings with the community, we plan to attend Wikimedia 2024 and explore avenues for facilitating public discourse on the potential impact of this work.

Evaluation

The study will be successful if it is completed according to the methodology. Evaluation should assess potential biases and limitations related to methods of data collection and analysis, including limitations of researcher's focus on English Wikimedia platforms.

Budget

A link to our budget spreadsheet is available [here](#).

Total requested: $24,250 USD

Response to reviewers and meta-reviewers

We are grateful for the thoughtful feedback and references from the reviewer team.

Reviewers inquired about authors' roles and complementary expertise. Howard is the lead researcher and a Wikimedia organizer, with previous publications focusing on Wikimedia research methodology and open source maintainer labor. Rasberry is a Wikimedia organizer and researcher, and will provide project advising on the Wikimedia community, methods, and data analysis. Since 2007 Rasberry has served on a clinical research advisory board for HIV vaccine research, and through that role, brings experience in supporting vulnerable research demographics to this project. Silberman is an award-winning author of *Neurotribes: The Legacy of Autism and the Future of Neurodiversity* (2015), and will provide project advising on characterizing and researching neurodivergent populations in the methods design, and contribute to analysis. Silberman will also provide feedback about crossover issues important to disability studies scholars and rights advocates.

Reviewers noted limitations of content analysis in comparison to interviews and survey techniques. Authors maintain that content analysis is a well established qualitative methodology for scoping out discussions within a new research area and surveying what this community has already published about itself, which can contribute to generalizable knowledge. Interview-based studies, particularly on populations that might be deemed "vulnerable" by Institutional Review Boards, require significant time, cost, and bureaucracy. We believe future researchers who seek to explore this research area through interviews, surveys, and/or computational techniques would benefit from our content analysis and research recommendations, which will establish a baseline by identifying this previously unexplored research domain, conversations surrounding neurodivergent editor experiences, and potential risks in conducting research on this population to help avoid harms or privacy infringements in future related work.

Reviewers also suggested a survey. We recognize the value of surveys, in addition to the high cost and time investment, a major consideration for why we did not select this method. Instead of conducting our own survey,

we aim to contribute to future WMF surveys, which would benefit from our research to establish ways of characterizing neurodivergent populations. This is addressed in the "Wikimedian Demographics" section of this proposal.

Regarding reviewers' questions about the feasibility of our content analysis, we have conducted a preliminary exploratory scan of existing public discussions on the research subject, finding at least 20+ public texts in English suitable for data collection.

Reviewers recommended addressing the potential biases in the content analysis, including self-selection. Example areas of interest we identify are the complexities surrounding *masking*, *camouflaging* and the disclosure and non-disclosure of neurodiversity-related identity characteristics and diagnoses (Davidson & Henderson 2010). We do want to clarify that the purpose of content analysis is to analyze existing public discourse in a particular forum, not to understand the range of privately held views. We welcome feedback about additional potential biases.

Reviewers recommended further risk analysis. We have addressed these concerns in the proposal's Risk section regarding not using direct quotes and focusing on paraphrasing/summarizing public texts. We have stated that we plan to solicit feedback from the community of Wikimedians in which we are embedded to understand potential risks and impacts.*~

References

Alm, P. A. (2014). Stuttering in relation to anxiety, temperament, and personality: Review and analysis with focus on causality. *Journal of Fluency Disorders*, 40, 5–21 https://doi.org/10.1016/j.jfludis.2014.01.004

Annabi, H., Sundaresan, K., & Zolyomi, A. (2017). It's not just about attention to details: Redefining the talents autistic software developers bring to software development. Proceedings of the 50th Hawaii International Conference on System Sciences. http://hdl.handle.net/10125/41827

Thomas Armstrong. (2011). *The Power of Neurodiversity: Unleashing the Advantages of Your Differently Wired Brain*. Cambridge, MA: DaCapo/Perseus Publishing Group.

Austin, R.D. and Sonne, T., The Dandelion Principle: Redesigning Work for the Innovation Economy, *MIT Sloan Management Review*, 55(4), 2014. http://mitsmr.com/1naHMdz

Biever, Celeste. Web removes social barriers for those with autism. *New Scientist*. June 27, 2007. https://www.newscientist.com/article/mg19426106-100-web-removes-social-barriers-for-those-with-autism/

Botha, M., & Frost, D. M. (2020). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health*, 10(1), 20–34. https://doi.org/10.1177/2156869318804297

M. Claudia Buzzi, Marina Buzzi, Barbara Leporini, and Caterina Senette. 2008. Making Wikipedia editing easier for the blind. In *Proceedings of the 5th Nordic conference on Humancomputer interaction: building bridges*, 423–426. https://doi.org/10.1145/1463160.1463210

Clarke A. E. (2005). *Situational Analysis : Grounded Theory After the Postmodern Turn*. Sage Publications.

Joyce Davidson, Autistic Culture Online: Virtual Communication and Cultural Expression on the Spectrum, *Social and Cultural Geography,* 9, no. 7 (November 2008): 791–806. https://doi.org/10.1080/14649360802382586

Davidson, J., & Henderson, V. L. (2010). 'Coming out' on the spectrum: autism, identity and disclosure. *Social & Cultural Geography*, *11*(2), 155-170. https://doi.org/10.1080/14649360903525240

Doyle, N. (2020). Neurodiversity at work: a biopsychosocial model and the impact on working adults. *British Medical Bulletin*, *135*(1), 108. https://doi.org/10.1093/bmb/ldaa021

Dyck, E., & Russell, G. (2020). Challenging psychiatric classification: Healthy autistic diversity and the neurodiversity movement. *Healthy minds in the twentieth century: In and beyond the asylum*, 167-187. https://doi.org/10.1007/978-3-030-27275-3_8

Fletcher, T. S., Chen, A., Pizarro, E. O., Norris, A., Tripp, M., & Tran, J. (2022). Sensory spaces on wheels: Meeting neurodiverse community members where they are. OT Practice Magazine. https://www.aota.org/publications/ot-practice/ot-practice-issues/2022/sensory-spaces-on-wheels

Gillespie-Lynch, K., Dwyer, P., Constantino, C., Kapp, S. K., Hotez, E., Riccio, A., ... & Endlich, E. (2020). Can we broaden the neurodiversity movement without weakening it? Participatory approaches as a framework for cross-disability alliance building. In *Disability alliances and allies* (Vol. 12, pp. 189-223). Emerald Publishing. https://doi.org/10.1108/S1479-35472020000001201 3

Glott R, Ghosh R, Schmidt P (2010) Wikipedia survey. Technical report, UNU-MERIT, Maastricht, Netherlands. Available: http://wikipediasurvey.org/. Accessed April 4, 2011.

Guberman, J. (2023). #ActuallyAutistic Twitter as a Site for Epistemic Resistance and Crip Futurity. *ACM Transactions on Computer-Human Interaction*, *30*(3), 1-34. https://doi.org/10.1145/3569891

Guberman, J., & Haimson, O. (2023). Not robots; Cyborgs—Furthering anti-ableist research in human-computer interaction. *First Monday*. https://doi.org/10.5210/fm.v28i1.12910

Hill BM, Shaw A (2013) The Wikipedia Gender Gap Revisited: Characterizing Survey Response Bias with Propensity Score Estimation. PLoS

ONE 8(6): e65782. https://doi.org/10.1371/journal.pone.0065782

Johnson, M. L. (2021). Neuroqueer feminism: turning with tenderness toward borderline personality disorder. *Signs: Journal of Women in Culture and Society*, *46*(3), 635-662. https://doi.org/10.1086/712081

Keyes, O. (2020). Automating autism: Disability, discourse, and artificial intelligence. *The Journal of Sociotechnical Critique*, *1*(1), 8. https://doi.org/10.25779/89bj-j396

Krcek, T. E. (2013). Deconstructing disability and neurodiversity: Controversial issues for autism and implications for social work. *Journal of Progressive Human Services*, *24*(1), 4-22. https://doi.org/10.1080/10428232.2013.740406

Krippendorff, K. (2018). *Content Analysis: An Introduction to Its Methodology*. Sage Publications.

Prince-Hughes, D. (2004). *Songs of the Gorilla Nation:My Journey Through Autism.* New York: Harmony Books.

Maroney, M. R., & Horne, S. G. (2022). "Tuned into a different channel": Autistic transgender adults' experiences of intersectional stigma. *Journal of Counseling Psychology*. https://doi.org/10.1037/cou0000639

Morris, M. R., Begel, A., and Wiedermann, B., (2015). Understanding the Challenges Faced by Neurodiverse Software Engineering Employees: Towards a More Inclusive and Productive Technical Workforce", *Proceedings of the 17th International ACM SIGACCESS Conference on computers & accessibility*. http://dx.doi.org/10.1145/2700648.2809841

Redi, M., Gerlach, M., Johnson, I., Morgan, J., & Zia, L. (2020). A taxonomy of knowledge gaps for Wikimedia projects (second draft). https://doi.org/10.48550/arXiv.2008.12314

Spiel, K., Hornecker, E., Williams, R. M., & Good, J. (2022, April). ADHD and technology research–investigated by neurodivergent

readers. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems*. https://doi.org/10.1145/3491102.3517592

Steve Silberman. (2015). *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*. Penguin.

Steve Silberman. The Geek Syndrome. *Wired.* December 1, 2001. https://www.wired.com/2001/12/aspergers/

Wikimedia Research. Knowledge Gaps Index. Meta-Wiki. July 22, 2020. https://meta.wikimedia.org/wiki/Research:Knowledge_Gaps_Index