

Investigating Neurodivergent Wikimedian Experiences

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Abstract

This project will focus on exploring discussions about being neurodivergent and participating in Wikimedia projects, including the strengths of being neurodivergent and contributing to Wikimedia and the challenges faced by neurodivergent Wikimedians. In Part I, we will conduct a content analysis of existing discussions about neurodiversity in the Wikipedia community. In Part 2, we will include the creation of a set of research design recommendations for future research on neurodivergent Wikimedians. The potential impact of this work is to increase understanding of how to support Wikimedian wellbeing.

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?* Existing studies on Wikimedia contributor experiences and demographics have neglected the representation of neurodivergent Wikimedians. Anyone interested in understanding the makeup of the Wikimedia community and supporting contributors, including organizers, technical support, and researchers, might be interested in this work.

Related work

Neurodiversity, Work, and Tech Work

Research on the obstacles faced by neurodiverse people at work, such as bullying, stigmas, discrimination, and anxiety (Alm 2014; Botha & Frost 2020) may be applicable. There is no data on how stigmas or discrimination might affect neurodivergent Wikimedians, although users have posted about related issues in public forums. Silberman has published about the convergence of people on the autism spectrum in computing careers (2001; 2015). 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).

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

Neurodiversity and Internet Culture

Davidson suggests that there are “distinctive autistic styles of communication” and discusses autistic peoples’ preferences for text-based communication (2008). Davidson focuses on how autistic people have flocked to online communities and created distinct autistic cultures online.

Wikimedian Demographics

Existing methods for studying demographic groups of Wikimedians will be consulted as we develop methods recommendations for studies on neurodivergent Wikimedians. The WMF has produced a number of editor surveys² that have not included questions about psychological wellbeing or neurodivergence. Our research might inform future iterations of the Knowledge Gap Index.

Methods

PART 1: Content Analysis

A content analysis of discussions about participating in Wikimedia and being neurodivergent will be conducted. Content analysis is a method to study discourse involving the creation of a corpus, followed by qualitative coding (Krippendorff 2018).³

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 interaction on Wikimedia platforms, threaded discussions, user boxes and categories are all content formats that may be included in the corpus. These texts 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.

² See:

https://meta.wikimedia.org/wiki/Category:Editor_surveys

³ Examples of research papers containing the type of content analysis we will employ include: Harlow, S. (2012). Social media and social movements: Facebook and an online Guatemalan justice movement that moved offline. *New Media & Society*, 14(2), 225-243.

Grounded theory will be employed, with qualitative codes created based on patterns in keyword usage, subjects discussed, framings, and other emergent properties in the corpus. We will interpret the results with care towards intersectional forms of marginalization.

PART 2: Further Research Design on Neurodivergent Wikimedians

Part 2 will involve exploring methodological considerations when designing studies about community representation and neurodivergent Wikimedians. This component of the proposal is necessary because the complexity and newness of this research area requires time spent investigating the best potential methods, and to evaluate potential bias and risks, as well as ways to involve the community. 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.

Expected output

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

Risks

Researchers will remove usernames from quotations to avoid privacy concerns. Researchers 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).

Community impact plan

We will produce recommendations about how to operationalize our findings. 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 for this Wikimedian demographic. The proposed work might inform those identifying ways to reduce Wikimedia's barriers to entry and accessibility.

Evaluation

The study will be successful if it is completed according to the methodology. Evaluation should assess potential biases, reproducibility, and other limitations.

Budget

- Lead Researcher stipend - \$15,000 USD
- Research Advisor stipend - \$5,000 USD
- Open Access journal fees - \$2,000 USD

Prior contributions

- Geiger, R., **Howard, D.**, & Irani, L. 2021. The Labor of Maintaining and Scaling Free and Open-Source Software Projects. *Proc. ACM Human-Computer Interaction* 5, CSCW1.
- **Howard, D.** & Irani, L. 2019. Ways of Knowing When Research Subjects Care. 2019. *Proc. SIGCHI Conference on Human Factors in Computing Systems*.
- **Howard, D.** 2014. Thoughts on Wikipedia Editing and Digital Labor.

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

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.

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.

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.

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.

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.

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*.

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.

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.

Guberman, J., & Haimson, O. (2023). Not robots; Cyborgs—Furthering anti-ableist research in human-computer interaction. *First Monday*.

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.

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.

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*.

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).

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/>