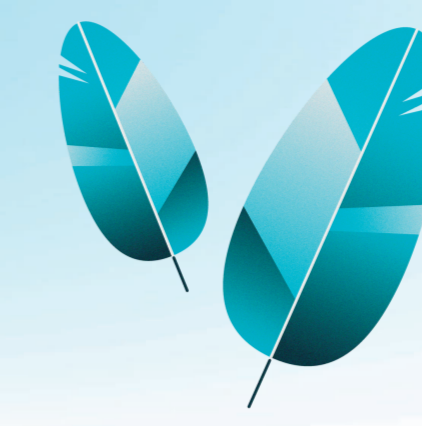


Moving away from ableism: Creating accessibility in youth mental health research

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Introduction

The U.S. Centers for Disease Control and Prevention defines disability as a condition that significantly impairs or limits one's ability to function in their daily life (2020). Globally, 190 million individuals age 15 and beyond were documented to experience disability in 2021 (World Health Organization, 2021).

Despite a high rate of individuals experiencing disability, youth mental health research is often inaccessible, as its methodology is often geared towards non-disabled individuals. This includes the co-design of research questions, study design, recruitment and sharing of knowledge. This creates barriers for diverse young people to participate in research and show up in ways that are not generalized and intended for a non-disabled person.

Without incorporating accessible research methodologies and acknowledging ableism, there is a risk for lack of representation and inaccuracy in the data gathered. Through co-creation, consultation and intentional implementation of accessibility measures in all parts of the research design and implementation, the inclusion of disabled and/or neurodivergent individuals can be done in a meaningful way.

Objectives

Moving away from Western models and a medical model approach towards disability, I hope to examine the methods in which accessibility can be established in youth mental health research, while acknowledging the systemic impacts of ableism.

Methods

I consulted with four disabled youth community advocates engaged in projects at Foundry, an integrated youth services organization, to understand what accessibility measures could be implemented and how ableism has been present in youth mental health research and care. The youth, of various equity seeking groups, were interviewed informally, using community based research practices; they were interviewed about their experiences as former academic research participants and their recommendations on what strategies can be used to allow research to be more accessible for disabled youth.

Additionally, I gathered knowledge and findings from academic research journals, along with other web sources. The inclusion criteria for academic articles were that they were in English and published between January 2000- August 2022. The research articles were found on the following databases:

- PsycInfo via EBSCO
- PsychExtra
- Ovid

The search terms used included “accessibility in research and disabled participants,” “promoting accessible research,” “accessible research methods,” “accessibility and equity in research” and “promoting inclusion, diversity, equity, and accessibility in research.” The review of academic literature was conducted to examine and identify current research methods implemented to allow for the authentic inclusion of disabled youth participants.

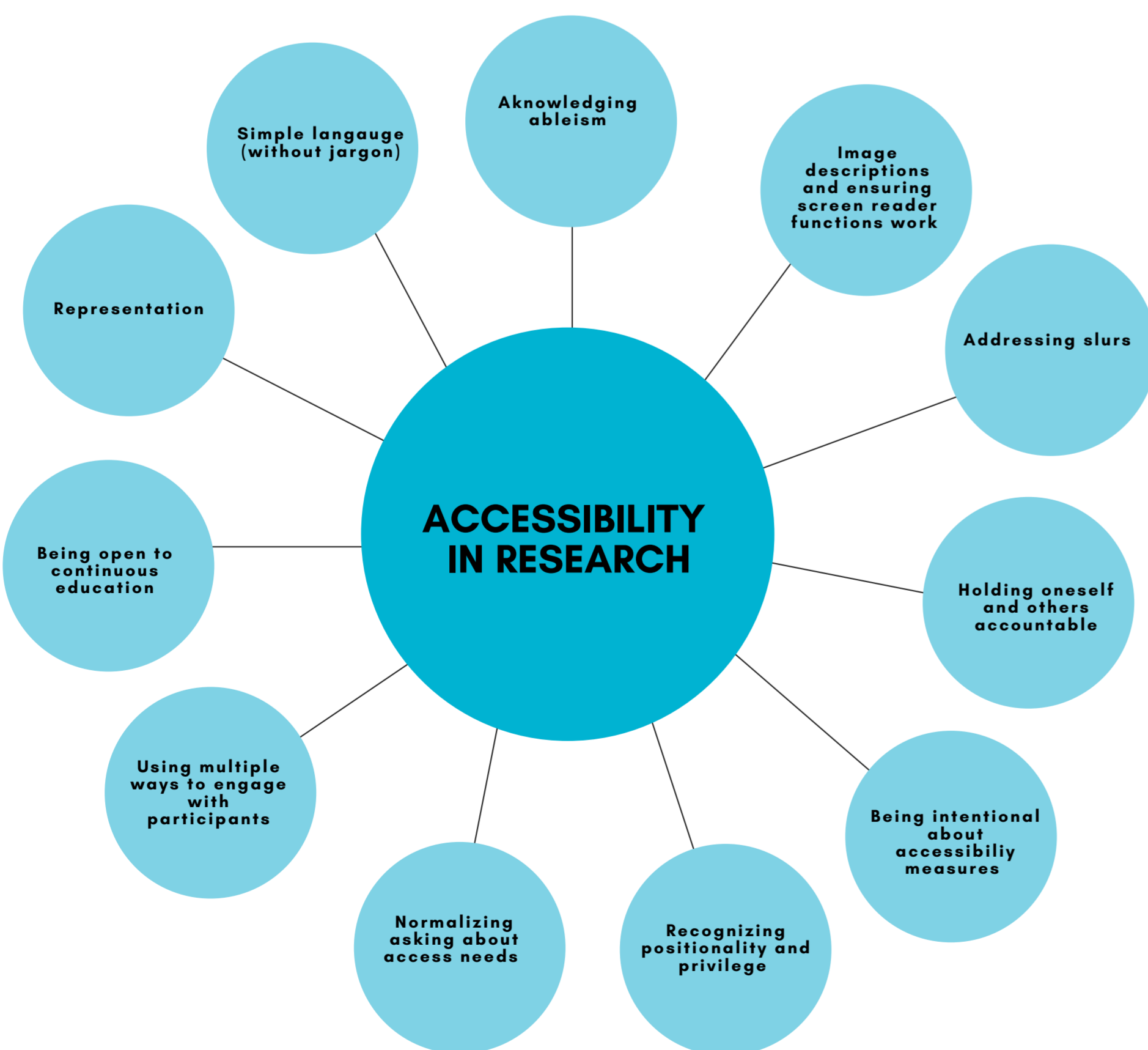


Figure 1: Ideas on how to make research more accessible for disabled and/or neurodivergent youth. Figure created by the first author for previous work on accessibility in research; full details available at <https://foundrybc.ca/accessibility-of-research/>.

Results

Based on the inclusion criteria, there were only six relevant articles found that examined accessibility in research. Out of the six academic articles, there were four articles that specifically shared accessibility concerns and recommendations for research to more authentically engage disabled participants. The remaining two articles did not specifically examine research in connection to accessibility, but explored the importance of accessibility in relation to trauma-informed practices and examining the experiences of ableism by disabled individuals.

Additionally, there were fewer than five web-based sources that explored accessibility in youth mental health, along with listing recommendations on accessibility measures that could be implemented in research. However, there were vastly more relevant web sources exploring the broader concept of accessibility measures for engaging with disabled individuals in research.

The findings of the review indicate there is limited published research literature that specifically examines how research can be made accessible for disabled youth. This suggests a notable gap in research literature and highlights an important area for further work. However, by sharing various accessibility strategies that can be easily implemented, seen in Figure 1 and Figure 2, there is hope that more voices can be authentically represented and engaged in youth mental health.

Authors/Source & Year Published	Shares Accessible Research Practices	Youth Specific Or Directed Towards No Specific Population	Academic Article Or Web Source
Bogart, K. R., & Dunn, D. S. (2019)	Yes	Not youth specific	Academic article
Boxall, K., & Ralph, S.	Yes	Not youth specific	Academic article
Conover, K. J., Israel, T., & Nylund-Gibson, K. (2017)	No	Not youth specific	Academic article
System Concepts (2021)	Yes	Not youth specific	Web source
Dee-Price, B. J. M., Hallahan, L., Bryen, D. N., & Watson, J. M. (2021).	Yes	Not youth specific	Academic article
Golden, T. L. (2022)	Yes	Not youth specific	Academic article
Grellmann, B.	Yes	Not youth specific	Web source
Henry, S. L., Abou-Zahra, S., & White, K. (2010)	Not specific to research	Not youth specific	Web source
Krolewski, S. (2021)	Yes	Not youth specific	Web source
Mann, G. (2022)	Yes	Youth specific	Web source
Monthly Educational Series Making Research Accessible to People with Disabilities. (2020)	Yes	Not youth specific	Web source
Olkin, R. (2004)	Yes	Not youth specific	Academic article
Ryals, B. & Pichora-Fuller, K. (2022)	Not specific to research	Not youth specific	Academic article
Thompson, S., Wickenden, M., & Cannon, M. (2021)	Yes	Youth specific	Web source
Youth Friendly (2021)	Not specific to research	Youth specific	Web source

Table 1: Relevant academic articles and web-based sources that examined accessible practices in conducting research with disabled individuals.



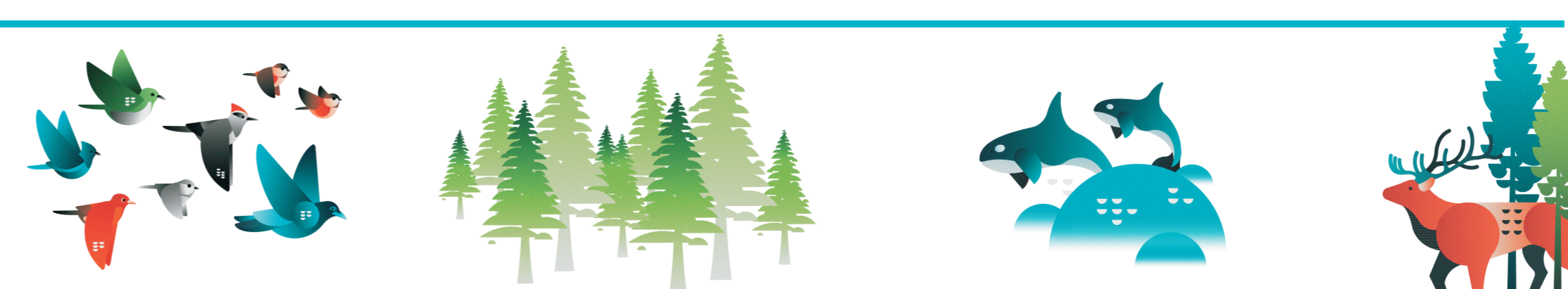
Figure 2: The image details multiple strategies shared, across four academic articles, on how to authentically engage disabled individuals in research.

Conclusion

The lack of co-creation in youth mental health had led to many disabled and neurodivergent people further being oppressed and harmed, having to fit into the standards of non-disabled individuals in order to have representation (Bogard & Dunn, 2019). Examining the state of accessibility in youth mental health research highlights the lack of meaningful or safe recruitment for disabled individuals, risking the opportunity to understand disabled individuals' experiences.

This work highlights the challenges of neurodivergent and/or disabled individuals having to abide by abled ways, and I propose solutions for research to be more accessible, allowing for those voices to be better represented. As there is a greater movement towards accessibility in the youth mental health space, allowing for the implementation of accessible research procedures is essential for all youth to engage in full and meaningful ways.

References
Bogart, K. R., & Dunn, D. S. (2019). Ableism special issue introduction. *Journal of Social Issues*, 75(2), 459-464. <https://doi.org/10.1111/josi.12294>
Bogart, K. R., & Dunn, D. S. (2019). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual and Developmental Disabilities*, 34(1), 41-54. <https://doi.org/10.1080/13682839.2019.1648396>
Conover, K. J., Israel, T., & Nylund-Gibson, K. (2017). Development and validation of the altered message scale. *The Counseling Psychologist*, 45(4), 570-590. <https://doi.org/10.1177/0022006717713317>
Dee-Price, B. J. M., Hallahan, L., Bryen, D. N., & Watson, J. M. (2021). Early experience exploring communication accessible research methods. *Disability & Society*, 35(2), 249-264. <https://doi.org/10.1080/09639267.2020.1715204>
Golden, T. L. (2022). Innovating health research methods, part II: Arts-based methods improve research data, trauma responsiveness, and reciprocity. *Family & Community Health*, 45(1), 150-159. <https://doi.org/10.1097/FCH.0000000000000337>
Grellmann, B. (2021). A comprehensive guide to accessible user research. Part 1: projects. <https://www.grellmann.com/blog/accessible-user-research-1/>
Henry, S. L., Abou-Zahra, S., & White, K. (2010). March: Accessibility, usability, and inclusion. Web Accessibility Initiative (WAI). Retrieved from <https://www.w3.org/WAI/fundamentals/accessibility-usability-inclusion/>
Krolewski, S. (2021). Why I'm preparing for inclusive research with people with disabilities. Medium. Retrieved from <https://medium.com/@krolewski/preparing-for-inclusive-research-with-people-with-disabilities-228a22b2b30c>
Mann, G. (2022). Accessibility of research. Retrieved from <https://foundrybc.ca/accessibility-of-research/>
Monthly Educational Series Making Research Accessible to People with Disabilities. (2020, July 14). Retrieved from <https://www.eric.gov/fulltext/ED599000/ED599000.pdf>
Olkin, R. (2004). Making Research Accessible to Participants with Disabilities. *Journal of Intellectual and Developmental Disabilities*, 29(4), 282-293.
Ryals, B., & Pichora-Fuller, K. (2022). Ear and Hearing. 43 (Supplement 1), 13-45. <https://doi.org/10.1097/AUD.0000000000000233>
Thompson, S., Wickenden, M., & Cannon, M. (2021, 2021). Ensuring research involving children with disabilities is inclusive, empowering and safe - what are the critical issues? Ethical Research Involving Children. Retrieved from <https://publications.combingthe3e.com/ethics-principles-of-research-involving-children-with-disability/>
U.S. Centers for Disease Control and Prevention. (2020, September 16). Disability and health overview. Centers for Disease Control and Prevention. Retrieved March 25, 2022, from <https://www.cdc.gov/od/oddisabilityandhealth/disability.html>
World Health Organization. (2021, November 25). Disability and health. World Health Organization. Retrieved March 25, 2022, from <https://www.who.int/news-room/factsheets/detail/disability-and-health>
Youth Friendly. (2021, December 31). How to meet access needs through outreach. Youth Friendly. Retrieved from <https://www.youthfriendly.com/blog/access-needs-youth/>



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