



Participation of People With Disabilities in Web-Based Research

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Web-based research has many advantages. However, the methods used may mean that people with disabilities are unable to participate. This paper aims to raise awareness and prompt researchers to think about accessibility in combination with their research.

Designing and conducting research that people, irrespective of their abilities, can access and participate in can constitute a considerable challenge. Yet, their participation is important, as concerns regarding non-representative study samples are well-documented (Frederick et al., 2012; Gill & Redwood, 2013; Scheifes et al., 2011; Schmidt & Vereenooghe, 2020; Shankar et al., 2018; Spaul et al., 2020; Zarin et al., 2005).

Where studies present a rationale for excluding participants with disabilities, two main reasons can often be identified: either a striving for homogeneous study samples or a reference to the task demands, implying that people with specific disabilities may not be able to complete them to a similar standard as people without such disabilities. Meanwhile, sample generalizability may not appear as essential for the internal validity of more theoretical or fundamental research than more applied research. Hence, from a research perspective, the representation of people with various abilities and impairments is not always considered an important condition of a study. This is in stark contrast with the human rights-based perspective and it concerns people with various abilities and impairments.

A Human Rights-Based Approach

The UN Convention on the Rights of People with Disabilities (CRPD) considers that disability “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation” and therefore stipulates that wherever possible reasonable adjustments should be implemented to erase discriminatory practices [United Nations, 2006, Preamble (e)].

For countries that have ratified the convention (United Nations, n.d.), which includes all member states of the European Union, the convention is officially binding, whereas signing countries, such as the United States of America, have merely expressed the intention to comply in a non-binding way. From the consideration that people with disabilities “should have the opportunity to be actively involved in decision-making processes about policies and programmes” [UN CRPD, 2006, Preamble (o)], it follows that researchers are not exempt from the responsibility to implement the UN CRPD (Ollerton & Horsfall, 2013). Therefore, it is imperative to consider how our choices of research methods may hinder or facilitate the inclusion of people with disabilities in psychological research to ascertain that our research findings meet the needs to reflect a diverse population.

Research Access and Accessibility

Whether the motivation to explicitly include or actively recruit people with various abilities and impairments in our studies follows our aims for a representative study sample or is guided by a human rights-based approach, their participation requires access to research and accessible research. To improve the access of people to participate in research, we can reflect on our recruitment practices. Hence, the call for more scrutiny of participant eligibility criteria and for addressing potential negative attitudes of researchers toward people with various abilities or impairments, particularly concerning participants who may lack the capacity to consent (Shepherd, 2020).

To improve the accessibility of our research, we can implement reasonable adjustments that facilitate the full and effective participation of people with different abilities and impairments. For example, Feldman et al. (2014) showed that while people with intellectual disabilities were excluded from over 90% of 300 surveyed medical and

clinical trials, reasonable adjustments could have made it possible for them to participate in seventy percent of them.

Web-Based Research to Promote Participation

In many ways, technology provides reasonable adjustments to facilitate the participation of people with various abilities and impairments, for example, through the use of alternative and augmented communication tools. For web-based research, including online surveys and experiments, a key benefit to researchers is that it offers them more opportunities to reach special or hard to reach populations (Reips, 2000), thereby increasing their chances to participate in research. Likewise, Citizen Science projects may further increase the access of non-researchers to research as participants or as lay-researchers assisting with data collection, for example.

However, in terms of Internet use, there is a digital divide between people with and without disabilities, both in terms of access and actual use, and people with intellectual disabilities are among those most impacted by the digital divide (Berger et al., 2010; Johansson et al., 2020). Consequently, it is important to consider how web-based research methods could also hinder people with various abilities and impairments and which adjustments could instead facilitate their participation.

Reasonable Adjustments to Improve the Accessibility of Web-Based Research

First, research has shown that implementing universal design principles (Story et al., 1998) and adhering to web-content accessibility guidelines (WCAG 2.1; W3C, 2018) can improve the accessibility of digital content and web-based applications for people with disabilities (Campoverde-Molina et al., 2020). These practices are perhaps the first steps researchers can take to facilitate the participation of people with various abilities and impairments. Wilson and colleagues further provide an excellent account of how web-based survey research could be made more accessible by combining multiple accessibility strategies (Wilson et al., 2013), while Goegan and colleagues offer guiding questions to assist researchers with reflecting on which universal design principles and reasonable adjustments could improve a questionnaire's accessibility (Goegan et al., 2018). As people with intellectual disabilities wishing to participate in research considered the lack of accessible research materials the main barrier to their participation, clinicians – and researchers alike – could benefit from more guidance on accessible research methods (Crook

et al., 2016). Together, these measures already take one step in reducing barriers for people with various abilities and impairments to participate in both web-based and face-to-face research.

Second, technological advances offer additional options to facilitate the inclusion of people with various abilities and impairments. For example, speech-recognition and text-to-speech services, as well as eye-tracking technology through built-in webcams, could enable people with sensory or motor impairments to navigate and complete web-based experiments and questionnaires. It can be expected that people relying on those technologies will have the necessary hardware, but then the software for web-based research is still required to be designed to make more active use of these technologies. While open-source products can reduce any financial barriers for researchers to improve the accessibility of their web-based research, these technologies raise new concerns in light of participant data protection and security.

A potential argument made against developing accessible web-based research is one of resources and incentives. Can it be expected that every researcher or research team has the knowledge, expertise, and time to design and conduct barrier-free research without professional incentives or legal action? Here, the division of scientific labor may offer a way forward. Or as Dattani and Bechhofer (2021) propose: "Although young scientists are becoming increasingly well-versed with some of these tools, we cannot expect every researcher to excel at all, or even most, of these skills voluntarily," and that such a level of specialization and distribution of labor and expertise "would reduce the burden of work placed on each researcher while increasing the quality and quantity of science conducted by researchers overall."

Conclusion

Calls for accessible research and to promote the inclusion of people with disabilities in study samples are not new. Recommendations for researchers generally include implementing universal design principles and modifying or optimizing study designs (Rios et al., 2016; Williams & Moore, 2011), which can be applied to face-to-face, as well as to web-based research. By combining this knowledge with the currently available technologies, web-based research can improve access to research and improve research accessibility for people with various abilities and impairments.

References

- Berger, A., Caspers, T., Croll, J., Hofmann, J., Kubicek, H., Peter, U., & Trump, T. (2010). *Web 2.0/Barrierefrei. Eine Studie zur Nutzung von Web 2.0: Anwendungen durch Menschen mit Behinderungen [Web 2.0/barrier-free. A study of the use of Web 2.0 applications by people with disabilities]*. Aktion Mensch e.V.

- Campoverde-Molina, M., Luján-Mora, S., & García, L. V. (2020). Empirical studies on web accessibility of educational websites: A systematic literature review. *IEEE Access*, 8, 91676–91700. <https://doi.org/10.1109/ACCESS.2020.2994288>
- Crook, B., Tomlins, R., Bancroft, A., & Ogi, L. (2016). "So often they do not get recruited": Exploring service user and staff perspectives on participation in learning disability research and the barriers that inhibit it. *British Journal of Learning Disabilities*, 44(2), 130–137.
- Dattani, S., & Bechhofer, N. (2021). *The speed of science*. <https://worksinprogress.co/issue/the-speed-of-science/>
- Feldman, M. A., Bosett, J., Collet, C., & Burnham-Riosa, P. (2014). Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. *Journal of Intellectual Disability Research*, 58(9), 800–809. <https://doi.org/10.1111/jir.12091>
- Frederick, K., Barnard-Brak, L., & Sulak, T. (2012). Under-representation in nationally representative secondary data. *International Journal of Research & Method in Education*, 35(1), 31–40. <https://doi.org/10.1080/1743727X.2011.609545>
- Gill, P. S., & Redwood, S. (2013). Editorials: Under-representation of minority ethnic groups in research-call for action. *British Journal of General Practice*, 63(612), 342–343. <https://doi.org/10.3399/bjgp13X668456>
- Goegan, L. D., Radil, A. I., & Daniels, L. M. (2018). Accessibility in questionnaire research: Integrating universal design to increase the participation of individuals with learning disabilities. *Learning Disabilities: A Contemporary Journal*, 16(2), 177–190.
- Johansson, S., Gulliksen, J., & Gustavsson, C. (2020). Disability digital divide: The use of the internet, smartphones, computers and tablets among people with disabilities in Sweden. *Universal Access in the Information Society*, 20, 105–120. <https://doi.org/10.1007/s10209-020-00714-x>
- Ollerton, J., & Horsfall, D. (2013). Rights to research: Utilising the convention on the rights of persons with disabilities as an inclusive participatory action research tool. *Disability and Society*, 28(5), 616–630. <https://doi.org/10.1080/09687599.2012.717881>
- Reips, U.-D. (2000). The web experiment method: Advantages, disadvantages, and solutions. In M. H. Birnbaum (Ed.), *Psychological experiments on the Internet* (pp. 89–118). Academic Press.
- Rios, D., Magasi, S., Novak, C., & Harniss, M. (2016). Conducting accessible research: Including people with disabilities in public health, epidemiological, and outcomes studies. *American Journal of Public Health*, 106(12), 2137–2144. <https://doi.org/10.2105/AJPH.2016.303448>
- Scheifes, A., Stolk, J. J., Egberts, A. C. G., Nijman, H. L. I., & Heerdink, E. R. (2011). Representation of people with intellectual disabilities in randomised controlled trials on antipsychotic treatment for behavioural problems. *Journal of Intellectual Disability Research*, 55(7), 650–664. <https://doi.org/10.1111/j.1365-2788.2010.01353.x>
- Schmidt, N. B., & Vereenooghe, L. (2020). Inclusiveness of cognitive bias modification research toward children and young people with neurodevelopmental disorders: A systematic review. *International Journal of Developmental Disabilities*, 1–16. <https://doi.org/10.1080/20473869.2020.1720156>
- Shankar, R., Rowe, C., Van Hoorn, A., Henley, W., Laugharne, R., Cox, D., Pande, R., Roy, A., & Sander, J. W. (2018). Under representation of people with epilepsy and intellectual disability in research. *PLoS One*, 13(6), 1–8. <https://doi.org/10.1371/journal.pone.0198261>
- Shepherd, V. (2020). An under-represented and underserved population in trials: Methodological, structural, and systemic barriers to the inclusion of adults lacking capacity to consent. *Trials*, 21(1), 1–8. <https://doi.org/10.1186/s13063-020-04406-y>
- Spaul, S. W., Hudson, R., Harvey, C., Macdonald, H., & Perez, J. (2020). Exclusion criterion: Learning disability. *Lancet*, 395 (10223), e29. [https://doi.org/10.1016/S0140-6736\(20\)30051-9](https://doi.org/10.1016/S0140-6736(20)30051-9)
- Story, M. F., Mueller, J. L., & Mace, R. L. (1998). *The universal design file: Designing for people of all ages and abilities*. NC State University.
- United Nations (n.d.). *Status of treaties. Chapter IV: Human Rights. 15. Convention on the Rights of People with Disabilities*. https://treaties.un.org/Pages/Treaties.aspx?id=4&subid=A&clang=_en
- United Nations General Assembly (2006). Session 61 Resolution 106. *Convention on the Rights of Persons with Disabilities A/RES/61/106*.
- W3C (2018). *Web Content Accessibility Guidelines (WCAG) 2.1*.
- Williams, A. S., & Moore, S. M. (2011). Universal design of research: Inclusion of persons with disabilities in mainstream biomedical studies. *Science Translational Medicine*, 3(82), Article 82cm12. <https://doi.org/10.1126/scitranslmed.3002133>
- Wilson, E., Campain, R., Moore, M., Hagiliassis, N., McGillivray, J., Gottliebson, D., Bink, M., Caldwell, M., Cummins, B., & Graffam, J. (2013). An accessible survey method: Increasing the participation of people with a disability in large sample social research. *Telecommunications Journal of Australia*, 63(2), 1–8. <https://doi.org/10.7790/tja.v63i2.411>
- Zarin, D. A., Young, J. L., & West, J. C. (2005). Challenges to evidence-based medicine: A comparison of patients and treatments in randomized controlled trials with patients and treatments in a practice research network. *Social Psychiatry and Psychiatric Epidemiology*, 40(1), 27–35. <https://doi.org/10.1007/s00127-005-0838-9>

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