

Strategies for Increasing Diversity of Representation in Autism Research: A Rapid Review

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Background/Rationale

- Autism research has historically excluded equity-deserving groups, especially Indigenous communities, racialized individuals, women, and individuals with disabilities, and continues to grossly lack diversity.
- Very little is known about the factors that contribute to this underrepresentation as well as strategies that can be implemented to recruit diverse audiences more effectively.

Research Question:

What strategies can be implemented to better accommodate racially and ethnically minoritized (REM) groups in autism research in Canada and the United States?

Methods:

- We followed guidelines set out by Cochrane Collaboration for rapid reviews
- Systematically searched and selected publications that focus on our research question.
- Included peer-reviewed English articles published in Canada and the United States.
- Extracted findings from **eight publications**.
- Grouped similar findings and strategies extracted from these publications

Targeted strategies for recruitment and retention, trust-building, and strategies implemented at the institutional level can increase diversity of representation in autism research



Results:

3 categories and 9 sub-categories :

1. Recruitment and retention of REM communities in autism research can be improved by:



- a) strategically selecting recruitment locations (e.g., primary care settings that serve these communities)
- b) using multimodal methods for recruitment and retention (e.g., emails, phone calls, recruiting in schools and churches)
- c) providing incentives and minimizing out-of-pocket expenses for participants
- d) designing research procedures and documents that reduce participants' time and effort.

2. Building and improving trust with the REM communities by:



- a) considering the historical considerations in healthcare and research
- b) creating an interconnected/bidirectional environment by involving community members throughout the process
- c) involving trusted researchers from REM, or adjoining/related, populations.

3. Strategies to implement at the institutional level:



- a) considering inclusive strategies with regards to team composition and training
- b) working with different levels of the organization, such as the research ethics board, to ensure that REM communities are not being excluded because of study design (e.g., exclusion criteria, design of research documents, and provision of incentives).

Conclusion:

Our rapid review synthesizes the current knowledge on strategies that can increase diversity and representation.

Ensuring that research studies are designed to include individuals they claim to support, will help to (re)shape how we think about childhood disability, especially with regards to inclusion, ultimately, resulting in research findings that are relevant to and impactful for a more diverse range of families.