Exploring the Lived Experiences of Racialized Parents Who Have Children or Youth with Disabilities: A Descriptive Case Study OntarioTech Grandview Kids

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Introduction

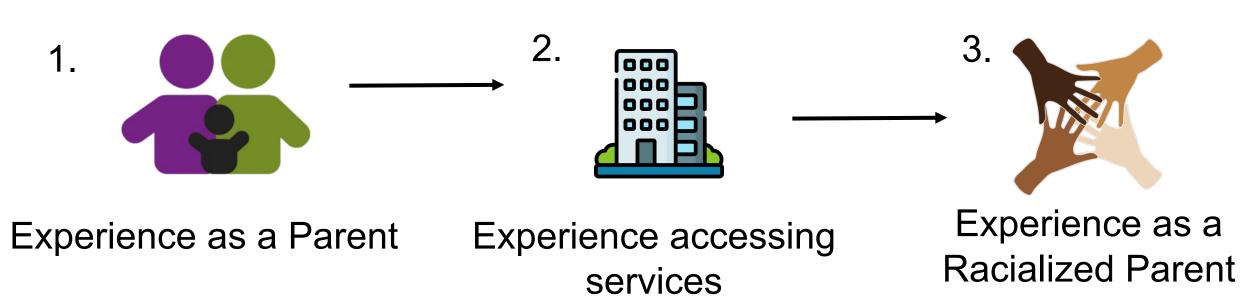
- Approximately 6.2 million Canadians aged 15 or older have one or more disabilities, and this number is expected to grow [1].
- From 2001 to 2021, the racialized population in Canada increased from 3.85 million to 8.87 million people [2].
- A major limitation is the lack of data on the intersection between race and ableism [3-4].
- There is limited knowledge on the interaction between race and disability, presenting a key knowledge gap [3-4].

Research Question:

From the perspective of racialized caregivers of children with disabilities, how does race impact the access of services in a community-based pediatric rehabilitation setting?

Methods

- Participants: 3 racialized mothers who had a child with a disability that were accessing services at Grandview Kids (aged 2-5, 6-12, 13-18), English speaking, and lived within the Durham Region.
- Methods: Multiple descriptive case study design. Consisted of three 45–60-minute individual, virtual, semi-structured interviews.
- Data Analysis: An inductive strategy was used to generate themes. NVivo 15 was used to analyze and organize themes into codes.



Conclusion

The results of this study highlight that race and disability affect the way that parents access pediatric rehabilitation services. Parents expressed they wanted to see culturally tailored services and more diversity in staff members to increase comfort levels This research will inform and guide the next steps to improve the delivery of services and programs.

Results "And then, unless you have a kid who was Judgement diagnosed, you don't really know they're just like oh the kids bad or you know... the kid needs licks, or needs discipline...' Ableism and Wait Times " ... They try to get everybody else to Formal start talking about it too with me to try to Diagnoses see if they can bully me into not doing it Lack of Support [the assessment] so telling me how could you think this about your kid?" "It would have done a lot for me to be Comfort Diverse able to speak to someone who I felt Service more comfortable with..." **Providers** Representation "I want to see you know, people who look like me..." "...And I don't think that my Perceived demographic's going to get it. I Program know I'm not." Racism **Wait Times** and "...All of the important people look a Scarcity certain way and communicate a certain Aging out of way and drive a certain agenda" services "...I just feel like it's just a group that doesn't look like me..." Belonging Cultural Support Groups "... You feel comfortable around Understanding people of a similar experience and cultural background or, you know they'd understand."

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[2] Hou, F., Schimmele, C., & Stick, M. (2023). Changing demographics of racialized people in Canada. Statistics Canada= Statistique Canada.

[3] Alegria, M., Vallas, M., & Pumariega, A. J. (2010). Racial and ethnic disparities in pediatric mental health. Child and Adolescent Psychiatric Clinics, 19(4), 759-774. https://doi.org/https://doi.org/10.1016/j.chc.2010.07.001

[4] Barnett, H. M., Patel, H. R., Fuentes, M. M., & Bunnell, A. E. (2022). Trends and disparities in inpatient rehabilitation of adolescents: the effect of demographics, injury characteristics, and facility type. Topics in spinal cord injury rehabilitation, 28(1), 13-20. https://doi.org/https://doi.org/10.46292/sci21-00033