

## **Challenges faced by Black mothers of children with developmental disabilities**

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### **Introduction**

Caring for children with developmental disabilities (DDs) can be challenging for a number of reasons, including social stigma, financial burdens, insufficient funding and programming, social isolation and limited social support from families and from communities as a whole. However, the challenges of raising children with DDs are even greater and complex if the families are from a racialized background.

Racialized mothers experience even greater stress. The stress of caring for a child with DDs is amplified as a result of racism, prejudice, stigma, and discrimination experienced by racialized families. We learned from our studies that racialized youth with DDs face barriers in key aspects of their lives, including health, mental health, education, work, and challenges of integration and community participation (Khan et al., 2025; Khanlou et al., 2024). Racialized families' distress is rooted in historic inequities they experience in healthcare, income, housing, education and social challenges, racism, and discrimination. For example, in Canada, Black families report experiencing higher rates of unemployment and income inequality, compared with the national average (Graham, 2025). They experience discrimination in employment, housing, education, and food insecurity (Graham, 2025).



### **Our Study**

This Information Sheet reports on findings from our study that explored health promotion strategies for racialized mothers of children/youth/ and emerging adults with DDs. We addressed the research question: What is an inclusive approach to health promotion for racialized mothers of school-age children and youth or emerging adults with DDs?

We conducted in-depth, qualitative, semi-structured interviews between January and December 2018. We interviewed seven Black mothers of children with DDs and three service providers. We asked questions related to racism, and about incidents mothers may have experienced while seeking or obtaining health care for their children or for themselves. We also asked about the challenges they face in promoting their families' health and well-being. Service providers' interviews focused on documenting their perceptions of the factors that are effective in promoting the health and well-being of racialized populations.

✚ The term “Black” refers to a diverse group of people from various ethnicities, backgrounds, and identities (Turner & Debrah, 2020).

✚ Black populations share a common African heritage, a common history of colonialism and slavery, and, consequently, the common present-day experience of anti-Black racism, resulting in socioeconomic, health, educational, and social disparities (Turner, Campbell & Debrah, 2020).

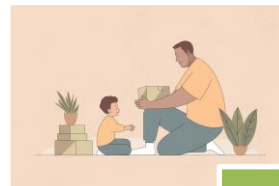
## **What did mothers tell us about their experiences of racism?**

Mothers of children with DDs reported numerous experiences of racism having started very early on in the mother and child's life and continued to persist. For example, mothers reported feeling a great sense of fear for the future of their children in the context of institutional racism, in the school system, and being targeted by police.

I always fear, especially when I watch the news, in terms of how Blacks are treated in the States... So we're very big on trying to foster his [son] speech because I'm always nervous that if he's walking down the street and he's not able to express himself, what would happen, especially with all the violence with the police and Black youth (P6 Mother).

Another mother discussed the constant support she needed to provide for her child with DDs in terms of communication:

My son can't articulate how he's feeling because of his learning disability and stuff like that, so I know that I have to be there to help him (P4 Mother).



In a study, Black American parents of children with intellectual and developmental disabilities reported facing prejudice and discrimination in terms of their race and disability (Magaña & Vanegas, 2021).

## **How is racism impacting mothers?**

Mothers reported that the challenges of mothering children and youth with DDs increased in complexity when they are racialized mothers. They explained that they did not have time for self-care.

The racism they experienced, in addition to the difficulties that come with mothering a child with DDs, contributed as barriers to their mental health, such as in relation to experiences of stress, depression and anxiety.

Racism in the context of raising a child with a DDs was affecting mothers' physical health and mental health and self-esteem, as expressed by these two mothers:

You go home, you're so upset, you go to work you're anxious you don't want to go. Even depression I could say (P1 Mother).

You feel like nothing, you feel like less than nothing... they look at you and talk down to you like you're a nobody. It's a terrible feeling (P4 Mother).



Families of children with developmental disabilities are weighed down by health care, transportation, and childcare costs and experience lower employment rates pushing families into poverty or preventing them from moving out of poverty (Magaña & Vanegas, 2021).

## **What supports do mothers need?**

Most of the interviewed mothers reported having completed post-secondary education (masters, university and college degrees). Some were raising two or more children with DDs on their own, without the support of close or extended family, friends, or support from the community.

Mothers often reported having little or no support for shouldering the care of their children and their health:

I don't get support. I have no social network systems available to me and that's the problem (P1 Mother).

A service provider noted that of the supports that do exist, most are not catered to the racialized community:

A lot of the sort of social supports that are available are not always applicable to the racialized mothers, so for example, if they have a parent group or something about mindfulness and stress reduction or something about teaching parents different skills or recreation/social activities, they don't always cater to people that come from diverse groups (P3 Service Provider).

## Recommendations

The following are some suggestions that Black mothers of children with DDs recommended to support their health and mental wellbeing:

- ✚ More participation and inclusion of racialized mothers in decision-making.
- ✚ Increase coverage/subsidies for mental health services and supports, and daycare.
- ✚ Create specialized agencies and services for racialized mothers of children with DDs that help promote their health and wellbeing.
- ✚ Increase representation of healthcare practitioners and service providers from racialized backgrounds.
- ✚ More information on how to navigate health and social service systems in Canada for racialized mothers of children with DDs.

## Selected References:

- Graham, J. (2025). A portrait of Black Families in Canada. A Brief Overview of Statistics related to Black families in Canada. The Vanier Institute of the Family. <https://vanierinstitute.ca/resource/a-portrait-of-black-families-in-canada/>
- Khan A, Khanlou N, Vazquez LM, Epstein I, Srivastava R & Vandeveld-Coke S. (2025). Nursing care for youth with intellectual and developmental disabilities in the times of COVID-19. *International Health Trends and Perspectives*, 5(2), 289–311. <https://doi.org/10.32920/ihtp.v5i2.2470>
- Khanlou N, Vazquez LM, Khan A, Hart M, Ohiku T, & Hutchinson N. (2024). Information Sheet 20: Racialized youth with developmental disabilities: Barriers to inclusion in services and education. Toronto, ON. York University. <https://nkhanlou.info.yorku.ca/files/2024/05/Info-Sheet-20.-May-2024.pdf>
- Magaña, S., & Vanegas, S. B. (2021). Culture, race, and ethnicity and intellectual and developmental disabilities. In L. M. Glidden, L. Abbeduto, L. L. McIntyre, & M. J. Tassé (Eds.), *APA handbook of intellectual and developmental disabilities: Foundations* (pp. 355–382). American Psychological Association.
- Turner, T., Campbell, P. & Debrah, M. (2020). *Jurisdictional Scan: Programs and Services for Black Parents in Ontario*. Toronto, ON: Turner Consulting Group Inc. <https://www.blackparenting.ca/reports.html>

## ABOUT THE INFORMATION SHEET

This information sheet is part of a series produced at our Office as part of the Intersectional Approach to Immigration Status, Gender and Disability Research Program. It provides some of the key findings from our recently completed qualitative study titled *Equity-Based Health Promotion Framework for Racialized Black Mothers of Children with Developmental Disabilities*.

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