Racialized caregivers of youth with developmental disabilities: Barriers to trust of formal systems and recommendations for effective strategies

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Introduction

This Information Sheet reports on select findings from our scoping review study (Khan & Khanlou, 2025), which examined effective strategies to address Triple Trauma in racialized parent caregivers of youth with DDs.

We define Triple Trauma as arising from experiences of caregiving, disability, and racism among racialized parent caregivers of youth with DDs (Khan & Khanlou, 2025). We consider how these experiences may affect access to essential resources and services needed to support their youth with DDs, and in relation to their overall health and well-being.

Many formal systems exist that shape an individual's experience in society. Formal systems that significantly impact supporting caregivers of youth with DDs include healthcare, education, and social services, which must work collaboratively to offer comprehensive care (Crossman, 2025). Healthcare, education, and social service systems work independently and collaboratively to provide essential support for caregivers and youth with DDs, including early diagnosis and intervention, tailored therapies, and access to government funding and resources. Current literature indicates a gap in culturally responsive care within formal systems.

Our Study

Using Arksey and O'Malley's Framework (2005) for conducting scoping reviews, we searched for peer-reviewed articles and grey literature published between January 2010 and August 2025 that focused on caregivers with racialized youth with developmental disability from Canada, the United States, the United Kingdom, Australia, and New Zealand.

Lack of trust of formal systems emerged as a key theme during the data extraction stage. We identified six articles (Burke, 2025; Dababnah, 2022; Espinosa, 2025; Khalil, 2025; Iadarola et al., 2019; Searing, 2015) from our literature search that showed lack of trust in formal and culturally appropriate systems among racialized caregivers of youth with DDs. Our findings show that many racialized caregivers do not trust formal systems and rely on informal systems.

The findings guide our research question into how Triple Trauma affects these caregivers and what effective solutions can be implemented.

Due to experiences of marginalization and racism within the healthcare system, Black people are less likely to trust and access primary healthcare settings often leading them to delay in seeking care until it is too late (Massaquoi & Mullings, 2021; McMackon, 2025).

Our findings emphasize the need for deeper insights into caregivers' mistrust of formal support systems and the importance of understanding the reasons behind their distrust.

Over an eight-year span, Black Canadians were hospitalized at higher rates than other groups (racialized and non-racialized) for treatable health conditions such as asthma, diabetes, and hypertension (Statistics Canada, 2025 as cited in McMackon, 2025).

What types of experiences do racialized caregivers with youth with DDs have within formal systems?

Establishing trust among caregivers within formal systems is essential for fostering effective therapeutic relationships, delivering high-quality care and achieving positive health outcomes. In formal settings, trust is built through policies and practices that ensure care delivery is organized, regulated, and standardized. It is vital to create an environment where open communication is encouraged and respected, allowing racialized caregivers to express their concerns and fears without fear of reprisal.

Caregivers reported experiencing negative interactions, especially with medical providers, due to a perceived lack of respect for their opinions (Iadarola et al., 2019). This can lead racialized caregivers to feel marginalized within these systems, fostering feelings of isolation and frustration. Consequently, this may result in their avoidance of seeking care (Figure1).

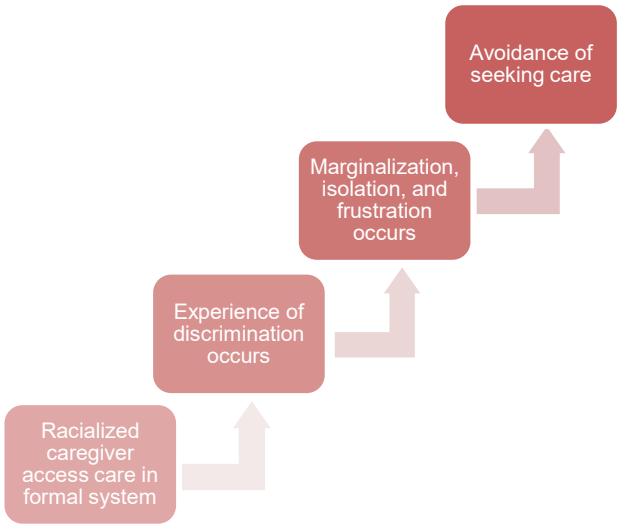

Figure 1: Racialized caregiver experience in formal systems

When caregivers feel undervalued and overlooked due to poor communication, cultural misunderstandings, and discrimination, the relationship between caregivers and service providers suffers. This erosion of trust can decrease engagement with healthcare and social services by caregivers as they may hesitate to seek help or rely on systems they believe do not address their needs.

What do we know about culturally relevant systems, and how can they operate in formal systems?

Culturally relevant systems effectively bridge the gap between caregivers and service providers. An essential aspect of these systems is the development of cultural responsiveness, which involves training workers to recognize their biases and to respect the cultural perspectives of those they serve (Iadarola et al., 2019). This approach could ensure effective communication as explained in Figure 2.

Using culturally appropriate language

Providing resources in multiple languages

Offering translation services

Figure 2: Approaches to ensure effective communication

Such practices not only help foster trust and understanding but also reassure us of the effectiveness of these systems in promoting a more inclusive and equitable system. Racialized caregivers of youth with DDs will feel more welcomed because they see representation of themselves and their lived experiences, further fostering a sense of belonging, and acceptance (Iadarola et al., 2019).

Formal caregivers, service providers and policymakers play a crucial role in the success of culturally relevant systems. These systems can thrive within formal frameworks by acknowledging and embracing diverse cultural backgrounds, traditions, and beliefs.

They promote inclusiveness, equity, diversity, respect, and overall societal well-being for various cultures. This not only enhances trust and communication between caregivers and providers but also empowers youth with DDs to make a significant impact on the formal system landscape

Effective Strategies/Recommendations

To build trust the current literature suggests several effective strategies as given in Figure 3.

Figure 3: Effective strategies to build Racialized Caregiver trust informal systems

Building collaborative partnerships

- Build a pathway for open communication where service users can reach out when they feel unsafe or discriminated against (Iadarola et al., 2019).

Promoting caregiver engagement

- Ensure that caregivers' voices are heard.
- Create services that reflect caregivers' lived experiences reflect the representation of community being served (Dababnah, 2022; Khalil, 2025).

Community education initiatives

- Make available information on DDs to the public.
- Avocacate for policy reforms that focus on rebuilding trust and enhancing service delivery (Dababnah, 2022; Khalil, 2025).

Selected References:

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ABOUT THE INFORMATION SHEET

This information sheet is part of a series of information sheets produced at the Office of the Women's Health Research Chair in Mental Health and in relation to Intersectional Approach to Families, Immigration, Gender, and Disability Research Program. It provides some of the key findings from our current study titled *Exploring Impact of Lifelong Caregiving: A Scoping Review of Effective Strategies to Address Triple Trauma in Racialized Parent Caregivers of Youth with Developmental Disabilities.*

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