Racialized Youth with Developmental Disabilities: Barriers to Inclusion in Services and Education

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Introduction

Racialized youth with Developmental Disabilities (DDs) face barriers in key aspects of their lives including work, education, health, and community participation. Racialized youth refers to youth who are non-White. The COVID-19 pandemic disrupted services and support to health and mental health for this population (Khanlou et al., 2023), increasing day-to-day challenges for them and their families and support networks. Families of racialized youth with DDs may have limited: 1) access to support to help them manage challenging situations; 2) resources to cope with stressors; and 3) opportunities to voice their concerns.

Racialized youth with DDs face "double stigma" in relation to their racial/ ethnic identity (e.g. Black) and their developmental disability (Ali et al., 2016). Our previous studies found that Black mothers with children with DDs were "triply" marginalized due to the intersections of gender (woman), racialization (Black), and caregiving (mother). Racism and discrimination affected mothers' access and utilization of social services (Khanlou et al., 2028). It is important to know the barriers that racialized families face to access services and support for their youth with DDs, and the facilitators that promote equity and support the health, mental health and wellbeing of this vulnerable population.

Our study

The goal of our project was to examine the barriers and facilitators of social support for racialized families of youth with DDs (ages 16-29 years) and to scope the literature on equity-informed best practices in social support. The project's main objectives were:

i) to conduct a review of the literature on the barriers and facilitators of social support for racialized families of youth with DDs; and,

ii) to conduct interviews with racialized (Black, East Asian, or South Asian) youth with DDs, with family caregivers, and with service providers, on inclusive social support during and beyond the pandemic.

In this Information Sheet we share findings from our scoping review and emerging research findings from our interviews. We report on two areas: services and education.
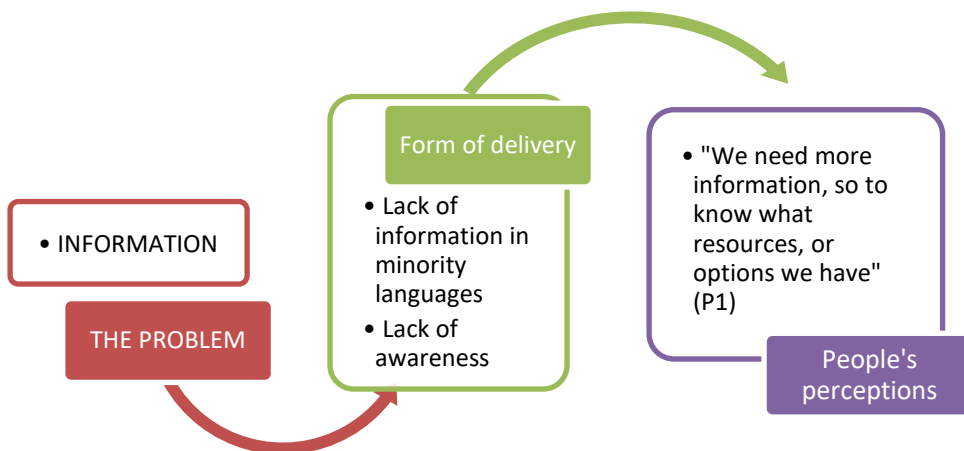
What did we do?

- We reviewed a total of 1, 129 sources and selected 28 eligible articles to be included in our review part of the study.
- We report on findings from an ongoing study. We interviewed 9 participants, of these 2 were young adults with developmental disabilities of Asian and Caribbean descent, 4 were immigrant Chinese caregivers, and 3 were service providers of Jamaican, Pakistani and Indian descent serving this community.
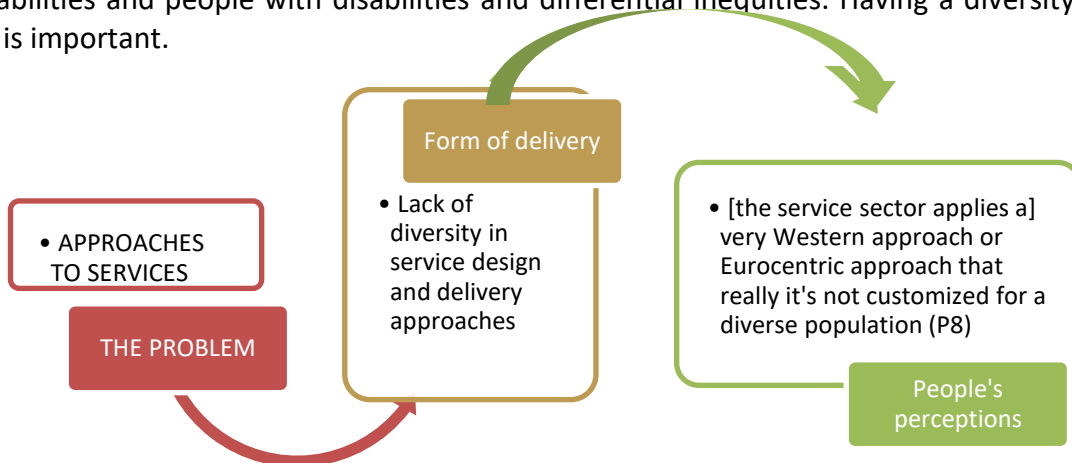
What did we find?

Barriers to Access Services

Families face barriers related to insufficient information on supports and services available in minority language, access to interpretation is also reported as minimal or absent. Caregivers voice their concern for the need to have a better communication with service providers. There are also socioeconomic inequities and financial barriers to accessing services.

- INFORMATION

  THE PROBLEM

  Form of delivery
  - Lack of information in minority languages
  - Lack of awareness

  - "We need more information, so to know what resources, or options we have" (P1)

    People's perceptions

Culturally relevant resources and approaches are needed in the service system. Decolonizing approaches to service delivery includes not only language but recognizing that there is a diversity in terms of the cultural understandings about disabilities and people with disabilities and differential inequities. Having a diversity of voices in program designing is important.

- APPROACHES TO SERVICES

  THE PROBLEM

  Form of delivery
  - Lack of diversity in service design and delivery approaches

  - [the service sector applies a] very Western approach or Eurocentric approach that really it's not customized for a diverse population (P8)

    People's perceptions

Barriers to Education

Stereotypes are key barriers to equity in education for Black students. Service providers reported that in the school setting, Black students with disabilities are labelled, and viewed, for their behaviour (P4). They are penalized for their behaviour, their specific needs are overlooked, and limited attention is given to their academic point of view.

DISCRIMINATION

"I think one of the challenges is going through the school system that people who are racialized deal with, is that discrimination happens even in a special needs population" (P4).

More education and training about developmental disabilities, within a broad spectrum of professional and service providers is needed. Caregivers pointed out that along education and training, what is needed is a better public recognition of professionals who are underpaid in the field of developmental disabilities. This leads to a high turnover of professionals creating challenges and inconsistency for families of youth with DDs.

TRAINING

I don't feel that the school was efficient in terms of training… there's no oversight, there's no supervision and classroom teachers do not seem to think that it is their responsibility" (P5).

More educational supports are needed. The lack of resources is due to the lack of funding from the government, which then impacts the level of support that the students can receive. Young people with DDs have limited programming and options for training. This is specially in the context of post-secondary education: young adults with DDs struggle to continue their education and training as the integrated classroom model does not include individualized supports as required for some of the students. More support is needed to address the challenges of advocacy for the parents/caregivers due to language and discrimination.

EDUCATIONAL SUPPORT

"There's a huge gap within the education system and special needs folks' parents are having to really fight for their child and advocate for their child. And I think that it's not just about lack of resources which we already know that there is a lack of resources within the public education system, but there's also a lack of awareness" (P7).

What did caregivers and service providers recommend?

MORE PARTICIPATION

Policy makers should learn from raciliazed families with DDs

• "Our experiences and our needs are definitely crucial to develop any program that works" (P1)

MORE TRAINING

More culturally competent training on developmental disabilities for service providers

• "There should be a core understanding [of developmental disabilities] that we learn before we go into the job" (P8)

Selected References

Khanlou N, Khan A, Vazquez LM, Pashang S, Gateri H, Ohiku T, Hutchinson N, & Alawiye R. (2023). Information Sheet 19: Social support for racialized families of children and youth with developmental disabilities: COVID-19 pandemic inequities. Toronto, ON. York University. https://nkhanlou.info.yorku.ca/files/2023/06/Info-Sheet-19.June-2023.pdf?x96015

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ABOUT THE INFORMATION SHEET
This information sheet is part of a series of information sheets produced at our Office and in relation to Intersectional Approach to Families, Immigration, Gender, and Disability Research Program. It summarizes key ideas from our study titled: Social support for racialized families of youth with developmental disabilities: Intersectionality informed research.

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