Social support for racialized families of children and youth with developmental disabilities: COVID-19 pandemic inequities

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Introduction

People with disabilities face increased risk for exposure, complications, and death from the recent COVID-19 public health emergency (Shapiro, 2020; Turk et al, 2020). The pandemic lockdown, with disruption of services and support (Chung, 2020) and accessibility barriers to prevention and response measures (Eshraghi et al., 2020), increased the challenges associated for people with developmental disabilities (DDs) (Ameis et al., 2020). Racialized people with disabilities (including DDs), further face systemic disadvantages across their social determinants of health (John et al., 2016); the interlocking barriers to care position them at a high risk of the effects of the COVID-19 pandemic. Our research findings suggest that social support mitigates the effects of stressors for families to promote the wellbeing of children / youth with DDs leading to positive outcomes (Khanlou et al., 2022; Khanlou et al., 2015).

Lack of data on the effects of the recent pandemic on people with DDs results in the inability of health surveillance systems to accurately determine the impact of the pandemic on marginalized populations and support needed (Turks et al., 2020). Increasing calls from racialized communities and disability advocates, scholars, and practitioners urge for the need to generate more data on the pandemic experiences of racialized people with DDs.

Our study

The goal of our project was to advance knowledge mobilization (KMb) through an equity-informed intersectoral lens on pandemic health disparities experienced by racialized families of people with developmental disabilities. The project's objectives were to conduct a Virtual Community Workshop on COVID-19 health equity for racialized families with DDs, and to engage in knowledge translation and mobilization for and with racialized families with DDs.

The Workshop participants included racialized families with DDs, racialized disability advocates, service providers, researchers, and students. The 17 participants shared their views on racialized families with DDs' experiences in access to social support in the pandemic context. Findings from our scoping review on social support for racialized families with DDs were shared to stimulate the discussion.

What is social support?

Racialized families with developmental disabilities bear a disproportionate burden of stress, illness, and health inequities (Bhardwaj et al., 2017). Social support entails access to material and psychological resources families can use to improve the overall wellbeing and quality of life of their children / youth with DDs.

Social support may be perceived or received and can be categorized into 4 domains of social support (House, 1981):

- structural - availability and access to services, or to information;
- instrumental – tangible support or assistance provided in active and practical way, e.g., monetary aid, help with housekeeping;
- emotional – psychological support from a trusted group or valued individuals such as family, friends, or health professionals; and
- perceptive – the perception that one is cared for and has assistance available.

What did we do?

We asked the Workshop participants to discuss:

1) What are the barriers and enablers for families with DDs to social support?
2) How has the COVID-19 pandemic impacted racialized families with DDs?
3) How can we address pandemic health inequities experienced by racialized families with DDs?

What did we learn?

The Workshop discussion shines a light on the systemic and institutional barriers that racialized families with DDs face when accessing social support. The barriers to social support include:

- ✓ Lack of adequate government funding
- ✓ Services and support are either unavailable and / or inaccessible
- ✓ Long wait times to access special needs and mental health care
- ✓ Systemic racism and discrimination
- ✓ Limited support from the school system
- ✓ Lack of interprofessional collaboration and coordination with families resulting in additional burden for families

Lack of available and accessible services for racialized families was highlighted as a key issue in providing inclusive social support (Workshop Discussions)

"Racialized families with DDs are not provided information on how to navigate the system: the process of form completion and what is available and accessible" (Workshop Participant # 1)

> "The government is not taking care of the needs of racialized families of youth with developmental disabilities" (Workshop Participant # 2)

Participants discussed about the inequities racialized families with DDs faced in the context of the COVID-19 pandemic. Participants specifically talked about the challenges families experienced relating to healthcare, education, and finances:

- Financial difficulties: no financial support for recreation and wellness activities for families experiencing poverty, which lead to more challenges for families
- Healthcare: language barriers, lack of culturally appropriate care, complicated and excessive documentation, and disruption of services
- Education: schools are not equipped for children with developmental disabilities and support for adjusting to online learning were not available

> It is very important for families to have support in a language the way they understand (Multiple Workshop Participants)

Participants recommended:

Racialized families face additional barriers to accessing support and services for developmental disabilities care. Workshop participants recommended the following:

- Increase government funding: this is essential as many racialized families with DDs experience financial challenges, so that parents do not need to choose between taking care of their child and leaving a job or working from home
- Promote support and services tailored to the specific needs of families with developmental disabilities
- Provide timely access to mental health care and social work services
- Access to non-biased and non-stigmatized culturally relevant healthcare and services that are secure and safe, for example:
    a. Understanding distrust and hesitancy towards vaccinations and respect for families preferred treatments
    b. Providing care in different languages
    c. Hiring bicultural / bilingual / racialized professionals
    d. Training professionals in culturally safe and equity-informed practices
- Develop inclusive DDs policy / programs that are relevant to the needs of racialized families children/youth with DDs

- Implement policies that are sensitive to the interlocking inequities experienced by racialized populations and support racialized families of children / youth with DDs

> "Most places that provide support do not tailor to specific groups that need support" (Workshop Participant # 3)

> Culturally appropriate care and services are needed (Multiple Workshop Participants)

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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 discussed in the Virtual Community Workshop from our study titled: Equity-informed intersectoral KMb to address pandemic health disparities experienced by racialized families with developmental disabilities.

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