

Equity-Based Health Promotion for Black Mothers of Children with Developmental Disabilities: Considerations for Practice and Policy during the COVID-19 Pandemic and Beyond

Diversity and Inclusion Webinar: Barriers to Services
Live to Air: Feb 10, 2021

Presenters: Ullanda Niel,¹ MD, CCFP and Nazilla Khanlou,² RN, PhD



AutismONTARIO

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² Women's Health Research Chair in Mental Health, Faculty of Health, Academic Lead, Meighen Wright Foundation Maternal Child Health Scholars Program, Associate Professor, School of Nursing, York University

Outline

1. Racialized Mothers study

- Background
- Challenges and strengths of mothers

Q & A

2. Practice and policy recommendations

- Recommendations for 'approaches to care' from 2018 Canadian consensus guidelines on primary care for adults with Intellectual and Developmental Disabilities (IDD)
- Examining current stressors regarding race, disability and Covid-19
- Encouraging change within our workplaces/places where we receive care

Q & A

3. Intersectionality-informed lens on impacts of COVID-19 on people with disabilities

Q & A



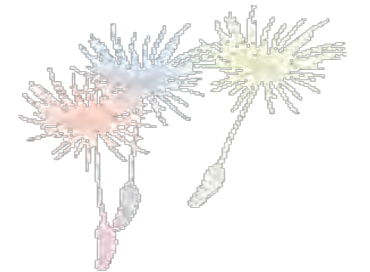
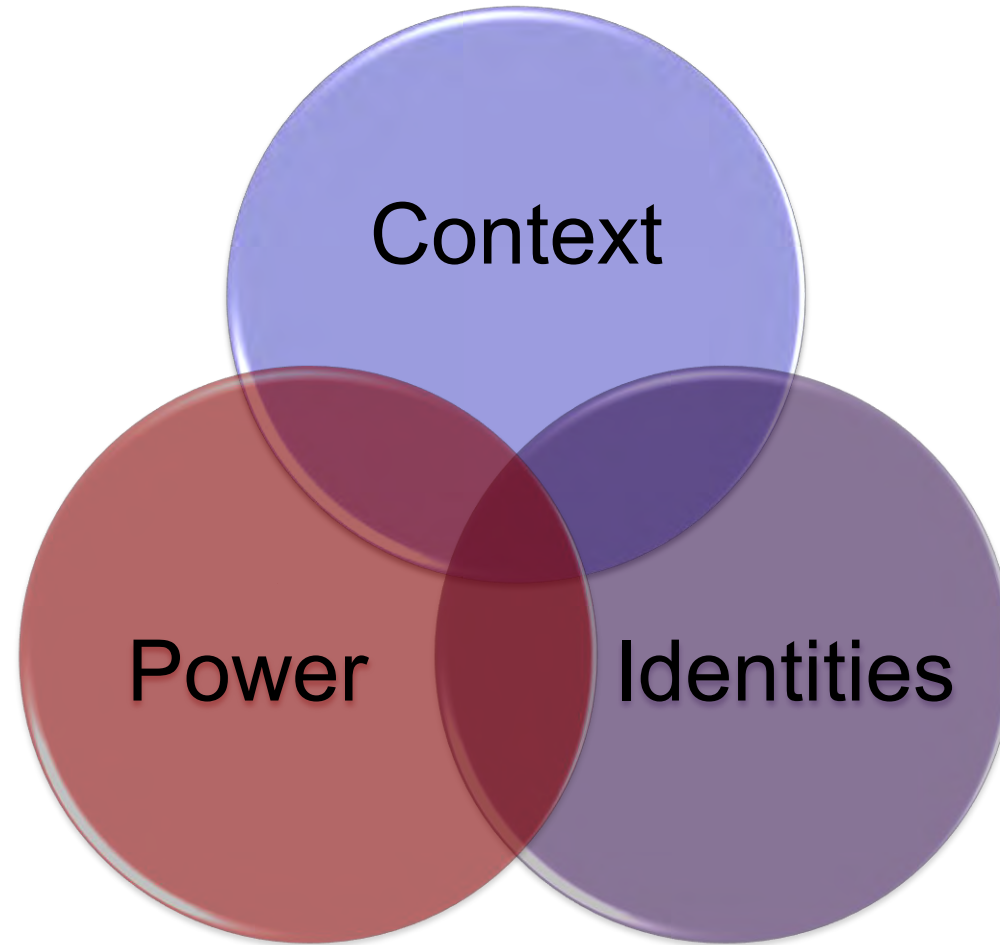
Autism Ontario

<https://www.autismontario.com/about-autism>

“As more research is being done on the intersections of autism and race, gender, sexuality and social locations, more information is being made available online which is increasing the rates of autism diagnosis in children and adults. This in turn is placing a larger demand on education, healthcare, and social service systems, highlighting glaring gaps in the supports available especially for autistic adults, people with lower incomes, people in rural areas, and Black, Indigenous and people of colour.”



Intersectionality



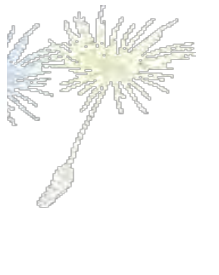
OUR PAST PROJECTS



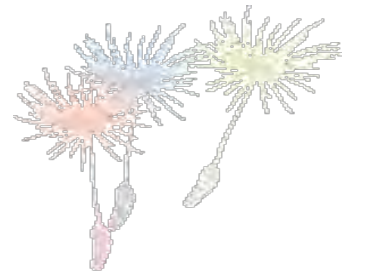
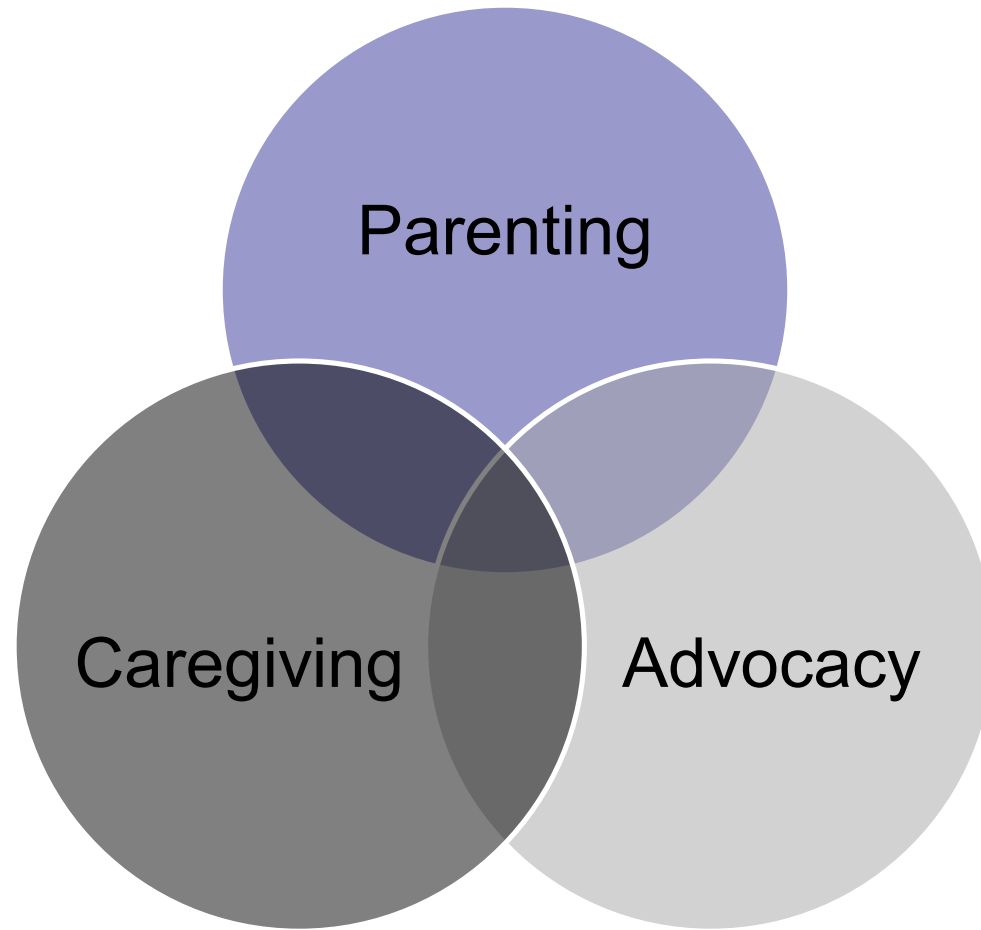
**VOICES OF IMMIGRANT MOTHERS OF CHILDREN
WITH DISABILITIES: AVAILABILITY AND USE OF
SOCIAL SUPPORT**



MOTHERS HEALTH PROMOTION PROJECT



Multiple Roles for Parents



RACIALIZED MOTHERS STUDY

Principal Investigator: Nazilla Khanlou, York University

TEAM MEMBERS

Gail Jones - Neighbours Allied for Better Opportunities in Residential Support

Hellen Gateri – MacEwan University

Deborah Davidson –York University

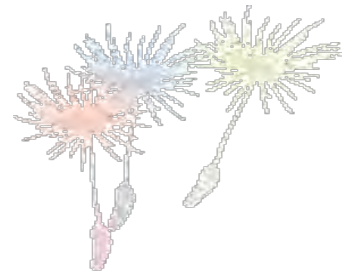
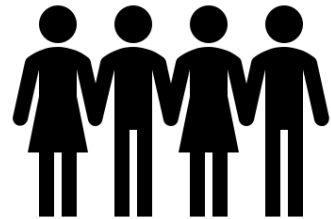
Masood Zangeneh – Humber College

Mahdieh Dastjerdi – York University

With Attia Khan, Luz Maria Vazquez & Tali Filler—York University



What is an inclusive approach to health promotion for racialized mothers of children and youth with developmental disabilities?



RECRUITMENT FOR A STUDY

Are you a Black Mother of a Child with a Developmental Disability?

We would like to invite you for an interview about your experiences raising a child with a developmental disability.

During the study interview we will discuss:

- The issues you face in raising a child with a developmental disability.
- How the issues impact your health and wellbeing.

Information shared during the interview will be **confidential**. As a token of appreciation for your participation, you will receive a **\$30 honorarium**.

For further details, please contact:

Luz Maria Vazquez
Tel: 416- 736-2100 Ext. 44527
Email: lvazquez@yorku.ca

Funded by Women's Xchange at the Women's College Hospital
The study has been approved by York University's Research Ethics Board

RECRUITMENT FOR A STUDY

Are you a Service Provider with experience serving black communities?

We you like to invite you for an interview about health promotion for black mothers of children with developmental disabilities.

During the study interview we will discuss:

- Challenges faced by black mothers of children with developmental disabilities.
- Types of health promotion strategies mothers recognize as inclusive and that have a positive impact on their health.

For further details, please contact:

Luz Maria Vazquez
Tel: 416- 736-2100 Ext. 44527
Email: lvazquez@yorku.ca

Funded by Women's Xchange at the Women's College Hospital
The study has been approved by York University's Research Ethics Board

Demographics of interviewed mothers

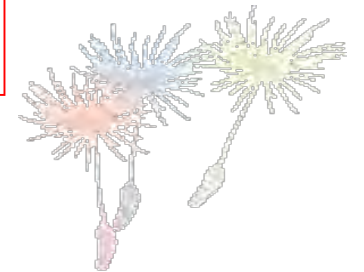
Character	Frequency or range
Country or region of origin	
Caribbean	6
Ghana (Africa)	1
Country of birth	
Canadian-born	4
Foreign-born	3
Age range	28-43 years
Marital status	
Single	5
Married living with partner	1
No of children with disability	1-3 children
Education level	
College certificate	4
Bachelor's degree	1
Master's degree	2
Employment	
Employed	3
Unemployed	4

Type of disability	ASD, <u>Tourette</u> Syndrome, Down Syndrome, ADHD, PDD, Learning disability, Dual diagnosis
Racial and ethnic group (in order of frequency)	Black, African American, African Canadian, Afro-Caribbean, Caribbean, African



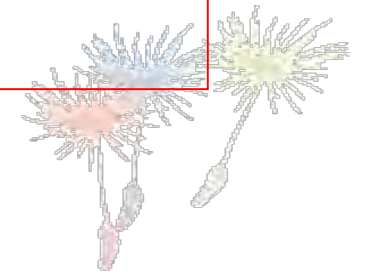
Challenges: Mothering

“I’m really stressed out all the time, it has affected me. I did stop working but I don’t feel good about it. I’m very worried about everything. I’m struggling financially, I’m going to go to court next week with the tenant board. I’m just overwhelmed but even when I work I feel it’s impossible to. It’s impossible with three kids” (P2).



Challenges: Mothering children with developmental disabilities

“I now know that I have to sacrifice a lot for them because they can’t speak for themselves. 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. As for my daughter [who has a DD], I make sure she has everything she needs that she doesn’t have to too much depend or have people treat her differently cause she’s a certain way. I make sure she’s where there are people that really care about her, so I don’t leave her with just anybody but overall, my patience and understanding” (P4).



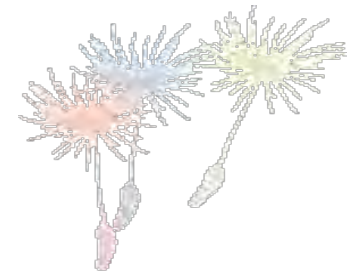
Challenges: Mothering children with developmental disabilities: Being Black or a racialized mother

“Well I was just annoyed like I don’t think the doctor had anything to do with it I just thought the guy that was serving me, he probably was just a little bit racist.... I think he just wasn’t serving me and he probably didn’t check me in and probably just had me waiting there cause he probably didn’t want me to get health service, I don’t know what his past experience or whatever, but maybe he didn’t want me to get treatment” (P5).



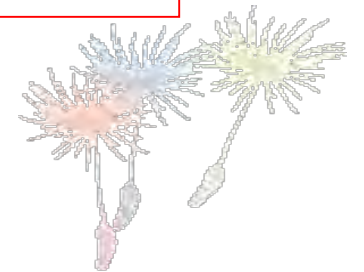
Challenges: No support from community, family or friends

“My support, I don’t know right now. I know there’s community support but personally, I’m withdrawn. My family’s not supportive, they don’t know how to be I guess... right now I’m not really doing much and I’m stressed out about finances” (P2).



Strengths: Intergenerational awareness and education about racism

“I just find that my experience I like to let my kids know what’s really happening, make them be aware that racism is real and that they shouldn’t allow certain things to happen because I believe I wasn’t really warned and my parents did experience a lot of racism and they didn’t tell me until like I was a lot older, like my mom got strip searched by the police, they accused her, said she was a man and strip searched her and violated her rights. She never told me these things until I was much older so I like to let my kids know like give them examples of little things so they know what’s racist and what’s not and what’s acceptable” (P2).



Strengths: Holistic approach to have a better society

“Exercising, good thoughts, good thinking habits, kindness, having love for people, regardless of how they feel about you” (P4).



Enter in Q & A Box:

- In your opinion what are some of the **strengths** and **challenges** of mothers raising children on the autism spectrum?

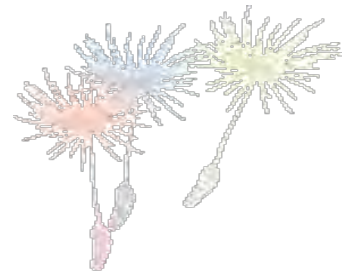


Project Video

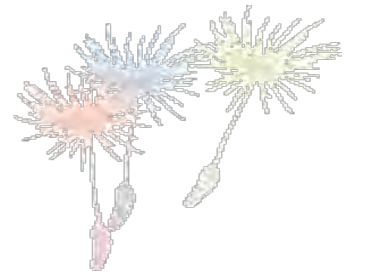
MOTHERING AT THE MARGINS: TOWARDS AN EQUITY-BASED HEALTH PROMOTION FRAMEWORK FOR RACIALIZED MOTHERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

The link to our video

<https://nkhanlou.info.yorku.ca/>



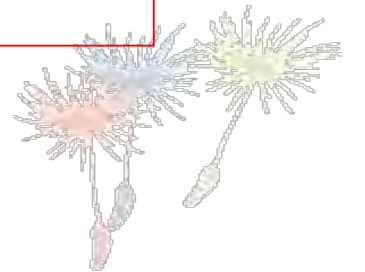
PRACTICE AND POLICY RECOMMENDATIONS BY MOTHERS



Mothers suggested:

Training/education/awareness for service providers about racism

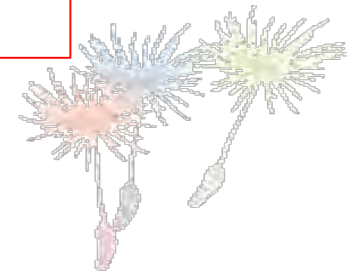
“Service providers need to know that racism is embedded within a social structure within Canada and that racism limits people’s access to certain services and once they’re aware of this, they would be able to know how to advocate on behalf of racialized people” (P1).



Mothers suggested:

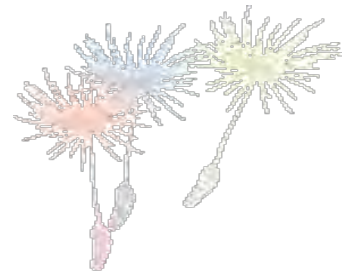
Participation and inclusion in decision-making

“By speaking with these people and finding out what their needs are... find the people with those issues because they would know better right? Formulating that plan and educating whoever is actually experienced those situations, and training them how to help other people with those situations” (p4)

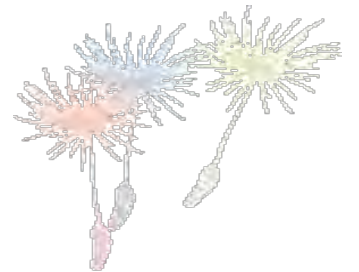
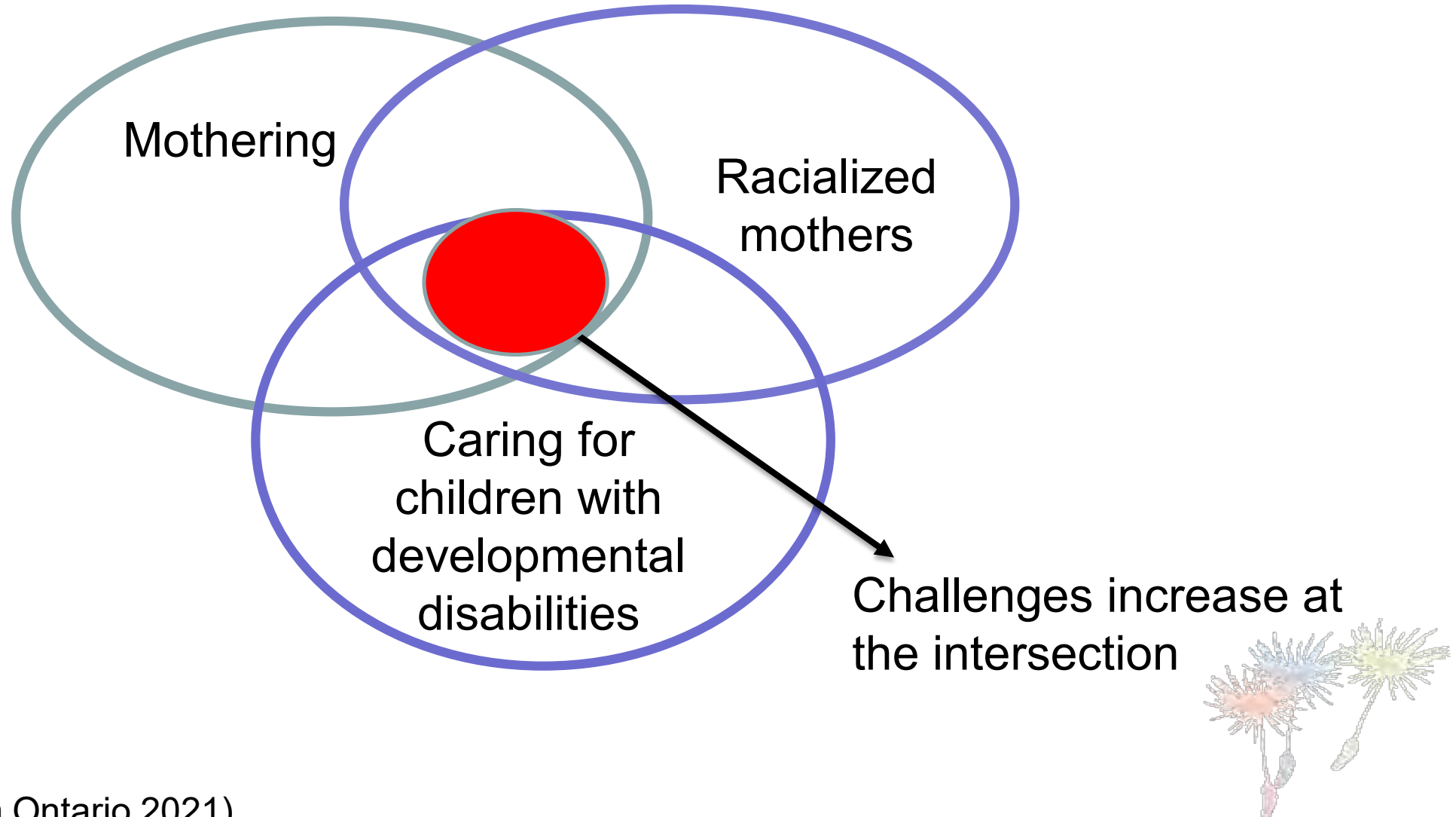


Other recommendations

- ✓ Service Providers with diverse backgrounds
- ✓ More information about services
- ✓ More Programming and services
- ✓ Hotline to support mothers

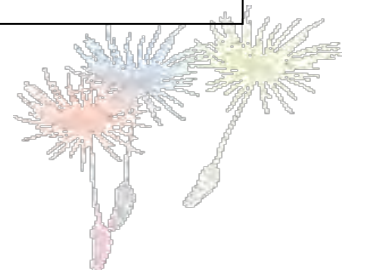


Conclusion



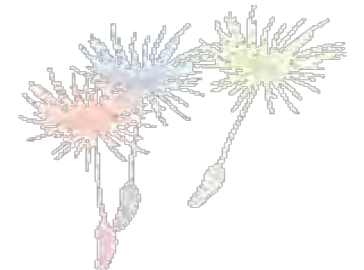
We would like to thank

The mothers and service providers who participated in our study,
Jahmeelah Gamble (on project video)
and
Women's College Hospital: The \$15K Challenge (funder)



Primary Care of Adults with Intellectual and Developmental Disabilities.

- 2018 Canadian consensus guidelines on primary care for adults with Intellectual and Developmental Disabilities (IDD)
 - Dr. William Sullivan, Surrey Place Center
 - Outlines standards of care to support clinical decision making including approaches to care, physical and mental health considerations.
 - Available:
 - Canadian Family Physician Vol 64, April 2018
 - <http://ddprimarycare.surreyplace.ca/guidelines/>





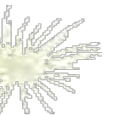
Search for Guidelines or Tools for Primary Care Providers



**About Developmental
Disabilities
Primary Care Program**

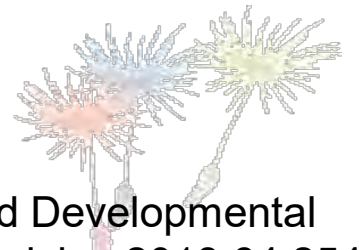
**Guidelines for Primary Care
of People with IDD**

**Tools for Primary Care
of People with IDD**



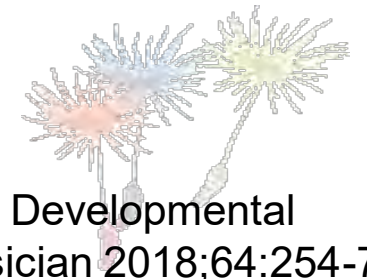
A Person-Centred Approach to Care

- Engage patients and caregivers
- Identify a support person
- Provide sufficient time
- Discuss goals and values



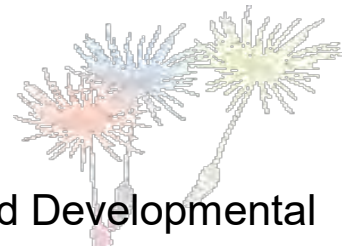
A Person-Centred Approach to Care

- Engage patients and caregivers
 - Understanding your patient's level of function
 - Tools for communication
 - Visuals/videos/ drawings/ easy to read handouts
 - Office organizational tools
 - Limiting time in the waiting room
 - Visits at beginning of day or right after lunch
 - Today's Visit



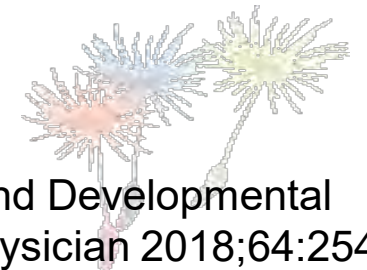
A Person-Centred Approach to Care

- Identify a support person
 - Supports patient autonomy
 - Attends healthcare appointments
 - Helps to coordinate care
 - Monitors ongoing health and social needs



A Person-Centred Approach to Care

- Provide sufficient time
- Discuss goals and values
- Advanced care planning
 - <https://ddprimarycare.surreyplace.ca/tools-2/covid-19-tools/covid-19-advance-care-plan/>



Caring for mothers and other caregivers

- **Screen for caregiver needs**
 - Regularly screen for and proactively attend to the support needs of caregivers.
 - Recommend interventions that reduce behaviours that challenge in people with IDD (e.g. positive behaviour support)
 - Increase coping and reduce stress experienced by caregivers

Sullivan WF. Primary Care of Adults with Intellectual and Developmental Disabilities. 2018 Consensus Guidelines. Can Fam Physician 2018;64:254-79.

Fairthorne J, Jacoby P, Bourke J, de Klerk N, Leonard H. Onset of maternal psychiatric disorders after the birth of a child with intellectual disability: A retrospective cohort study. J. Psychiatr. Res 2015; 61:23-30

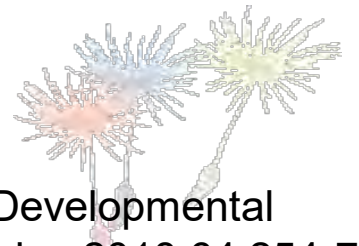
Increasing coping/ reducing stress for mothers

- Mindfulness based stress reduction
- Patient/client driven groups/ seminars



Caring for mothers and other caregivers

- **Monitor family or caregiver stress**
 - When concerns arise, assess and monitor family or caregiver stress and advocate for respite or additional supports
 - Standardized inventories: Brief Family Distress Scale
 - Informal questions at visits: “How are things going?”



Stressors in my patient population

- Poverty (including working poverty)
- Employment at high risk of Covid-19 exposure
- Precarious housing
- Interaction with law enforcement
- Interaction with child protective services
- Need for education/support
- Neighbourhood safety
- Social connectedness/ isolation
- Complex needs of new immigrants
 - Immigration challenges
 - Healthcare coverage (OHIP/IFH)
 - Language barrier
 - Core housing need



Disability and Race

For Mothers Of Black Children With Disabilities, Living With Twice The Fear



Allison Norlian Contributor

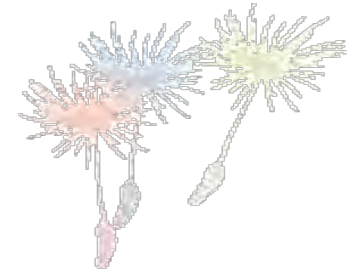
ForbesWomen

I write about women impacting disability and vulnerable communities.



Kim Kaiser and her son who has autism. KIM KAISER

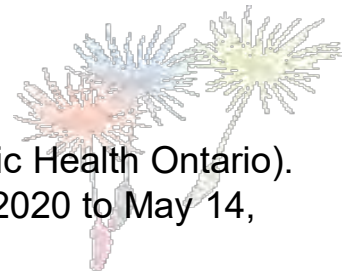
Allison Norlian,
Forbes Magazine.
June 9, 2020



Covid-19 and Race

- The most ethno-culturally diverse neighbourhoods in Ontario, particularly in large urban areas, are experiencing **higher rates of COVID-19 and related deaths** compared to neighbourhoods that are less diverse.
- COVID-19 infections in the most diverse neighbourhoods **3x higher** than in less diverse neighbourhoods
- People living in the most diverse neighbourhoods were also more likely to experience **severe outcomes of COVID-19**
 - Hospitalization 4x higher
 - ICU admission 4x higher
 - Death rates 2x higher

Ontario Agency for Health Protection and Promotion (Public Health Ontario).
COVID-19 in Ontario – A Focus on Diversity: January 15, 2020 to May 14, 2020. Toronto, ON: Queen's Printer for Ontario; 2020



Covid-19 and Race

Toronto

Black people and other people of colour make up 83% of reported COVID-19 cases in Toronto



21% of reported cases affect Black people, who make up only 9% of the city's overall population

Jessica Cheung · Posted: Jul 30, 2020 1:50 PM ET | Last Updated: 4 hours ago

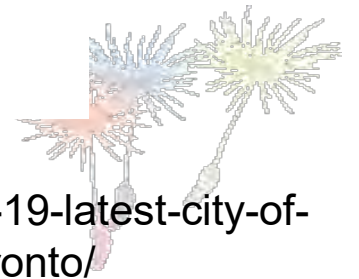
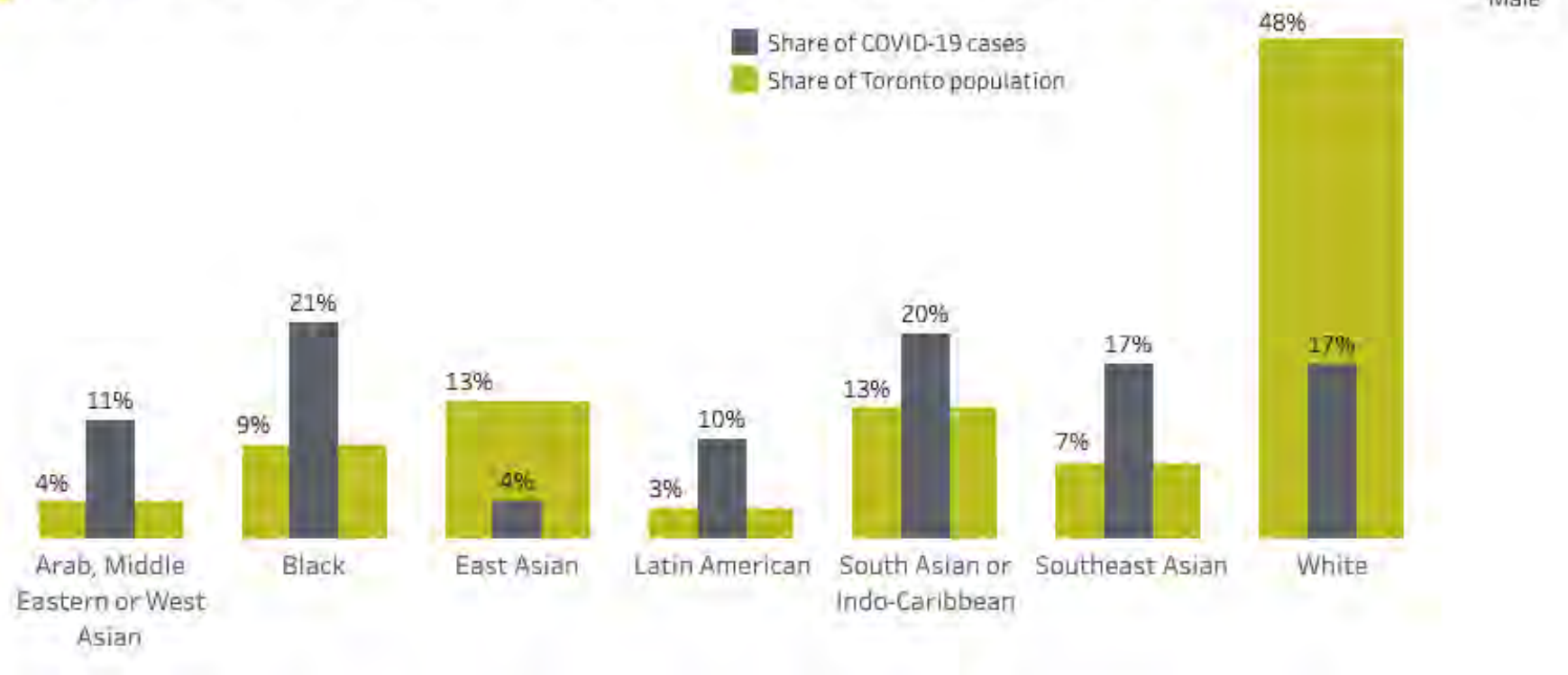


Toronto Public Health presented new data trends Thursday that show racialized and lower income communities in the city are disproportionately affected by COVID-19. (CBC/Radio-Canada)



Covid-19 and Race

Share of COVID-19 cases among ethno-racial groups compared to the share of people living in Toronto, with valid data up to July 16, 2020 (N=3,861)



<https://www.toronto.ca/home/covid-19/covid-19-latest-city-of-toronto-news/covid-19-status-of-cases-in-toronto/>

Covid-19 and Race

Report Findings

01

Compared to the Canadian average, Black Canadians report far worse health outcomes related to COVID-19.

- Black Canadians are more likely to report COVID-19 symptoms, either themselves or someone they know, more likely to say they sought treatment for COVID-19, and nearly three times as likely (21% to 8%) to report knowing someone who has died due to the virus.

02

Although further research is needed, poorer health outcomes for Black Canadians may be explained by greater exposure at work to the virus.

- Black Canadians are much more likely to report their job requires them to work with people face-to-face (Net: +41 vs. +25 national average).
- Black Canadians are more likely to feel that no matter what steps they take, their day-to-day routine puts them at an uncomfortably high risk of catching the virus (Net: -2 vs. -17% national average.)
- Black commuters, those who go in to work at least part-time, are much more likely than the national average to report symptoms, to seek medical treatment, and to admit themselves or know someone admitted to the hospital.
- Black commuters are twice as likely than the average Canadian worker to say their commute is unsafe (24% vs. 12%). This may be because Black Canadians who commute to their work are also twice as likely to use public transit than the average Canadian (25% vs. 12%).

03

Black Canadians report much worse financial impact from COVID-19 than the average Canadian.

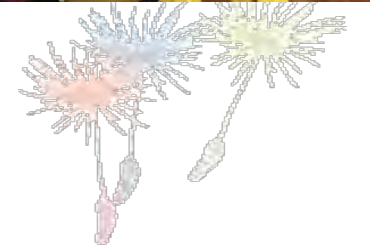
- Black Canadians are more likely to report layoffs or reduced working hours in their household (56% to 43%) and more worried, over the next few months, about paying their rent (45% to 36% national average).
- Black Canadians are also more likely than the average Canadian to say their household finances have been negatively impacted by COVID-19. And when it comes to age and gender, it's Black men over 45yrs who are most negatively impacted by COVID-19 when it comes to household finances.



Accessed Online: <https://innovativeresearch.ca/wp-content/uploads/2020/09/ACCEC01-Release-Deck.pdf>

How can I encourage change?

- Consider the **programming** offered by your agency
 - Do the materials used include Black people?
 - Do you celebrate or discuss important moments for Black Americans in your agency?
 - Do you offer culturally appropriate food options?
 - Do you have a diverse music selection for dance or fitness classes?



How can I encourage change?

- **Create publications and resources** that include the images of people of colour (social stories, pamphlets and handouts)



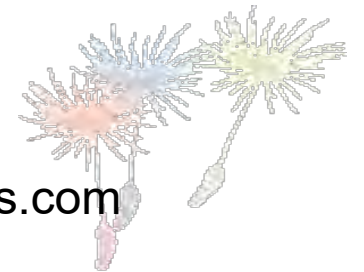
Wearing My Mask During COVID-19



By Heather Androsoff

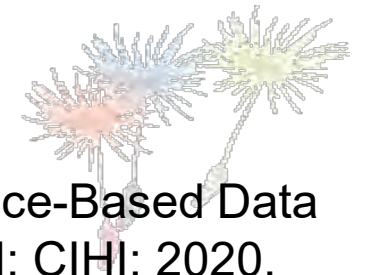


Socialstories4kids.com



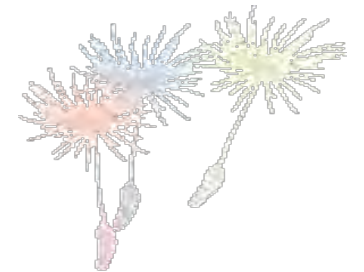
How can I encourage change?

- Understand the patient population in your area: consider collecting **race/ethnicity based data** to monitor for **health inequities** and to understand the impact of health outcomes, policies, programs and practices in on population subgroups



How can I encourage change?

- Include Black people and other marginalized groups in your **research and quality improvement** measures.

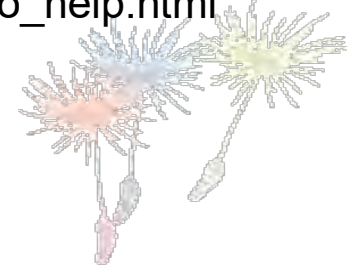


How can I encourage change?

- **Hire staff** that reflects the diversity of your patient population and provide an **inclusive culture** to support diverse staff members.

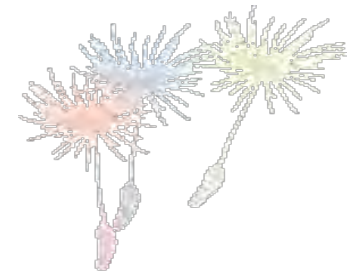


Robert, J. 2016. Doing my part to help physician workforce reflect diverse population. American Academic of Family Physicians accessed online at: https://www.aafp.org/news/blogs/freshperspectives/entry/doing_my_part_to_help.html

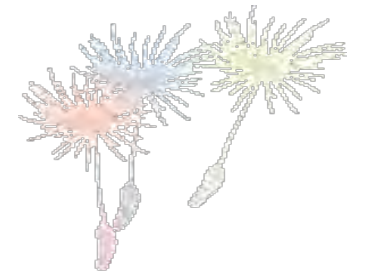
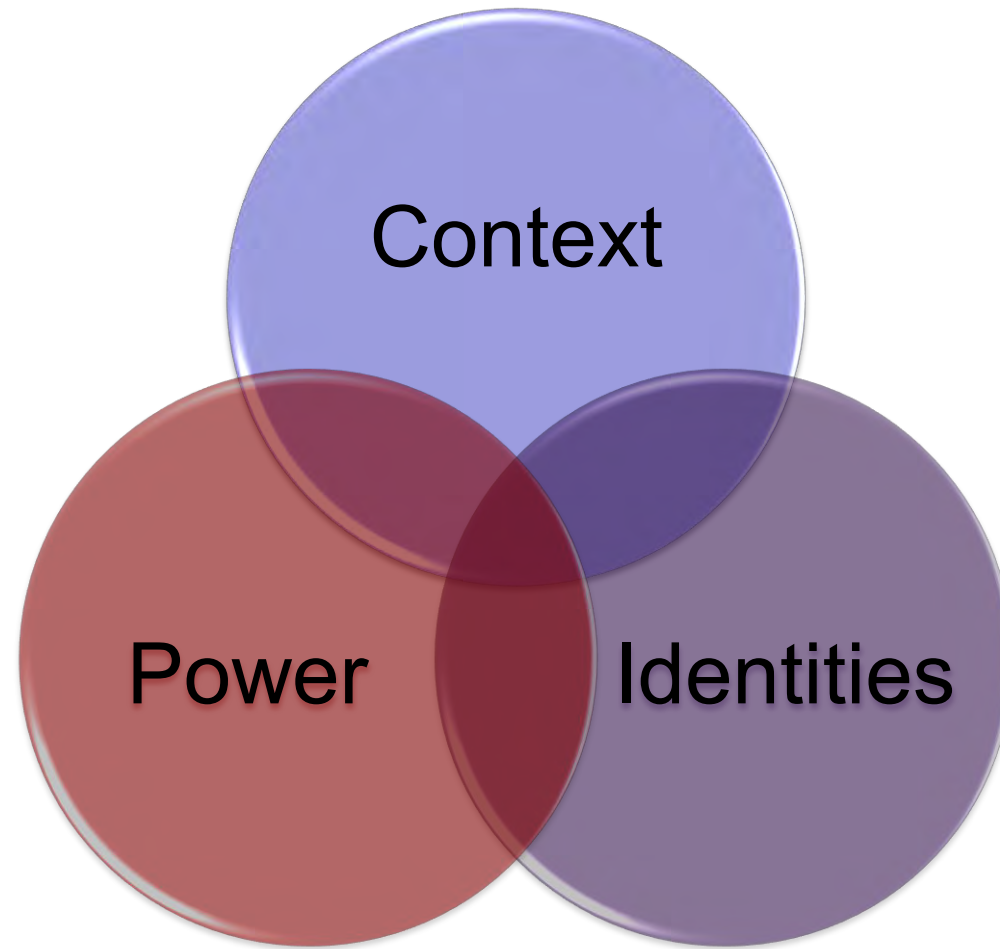


Enter in Q & A Box:

- What has your organization been doing well when combating systemic racism?
- How can you do better? What barriers do you anticipate?



Intersectionality

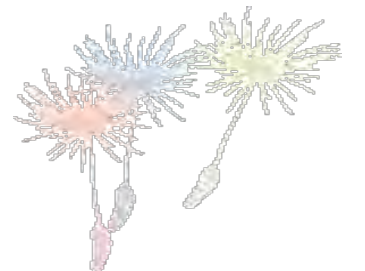


Intersectionality

Intersectionality as a Research Lens e-module

from Women's Xchange at Women's College Hospital

<http://womensxchange.womensresearch.ca/assets/emodules/IntersectionalityasaResearchLens/story.html>



Intersectionality-informed lens on impacts of COVID-19 on people with disabilities

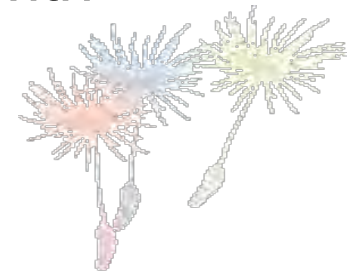
- In the COVID-19 pandemic, people with disabilities **face increased risk of exposure, complications and death** [UNICEF, n.d.].
- They also face **accessibility barriers** to prevention and response measures [UNICEF, n.d.].
- Limited data on people with disabilities results in the inability of surveillance systems to accurately determine the impact of current states, such as the COVID-19 pandemic [UNICEF, n.d.].

UNICEF, "COVID-19 Response: Considerations for Children and Adults with Disabilities," pp. 1-9, n.d.



Intersectionality-informed lens on impacts of COVID-19 on racialized people with disabilities

- Intersections related to **gender, race, ethnicity, socioeconomic status, sex, migration status and disability** shape both impacts of the pandemic on the population, as well as their resilient capacities.
- **People with disabilities have historically been socially and economically excluded.** They face multiple social and economic barriers that negatively impact their health, mental health, and wellbeing.
- The COVID-19 pandemic is exacerbating health inequities among specific populations, such as racialized families who have family members with developmental disabilities.

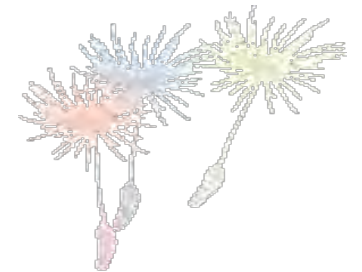


For further information about our projects:

Website: <https://nkhanlou.info.yorku.ca/>

Email: owhchair@yorku.ca

Twitter: <https://twitter.com/YorkUOWHC>
<https://twitter.com/NazillaKhanlou>



Enter in Q & A Box:

- In your opinion how can service providers support the wellbeing of Black mothers raising children on the autism spectrum during the COVID-19 pandemic?

