



Grandview Children's Centre Application for Approval of a Research Study

Project Title & Nickname	"Navigating the Medical and Social Merry-Go Round": Understanding the Caregiving Experiences of Parents of Visible Minorities that care for Children Living with Autism Spectrum Disorder (ASD)
Principal Investigator, Affiliation & Contact Information	Dr. Fiona Moola Holland Bloorview Kids Rehabilitation Hospital, Ryerson University, University of Toronto fmoola@hollandbloorview.ca Fiona.moola@ryerson.ca
Ethics Approval (Please provide details and attach the certificate)	Ethics approval has been received from Holland Bloorview Kids Rehabilitation Hospital.
Has the project received funding?	SSHRC – Insight Grant through Ryerson
Identify your projected timeline for this study. (start & end dates) *Please also specify the time period for recruitment and until what date you want the study advertised	October 2019 – March 2021 October 2019 – January 2021 – Study advertisement & Recruitment
Abstract (general abstract of the project)	In this study, we will explore the caregiving experiences of parents of visible minorities residing in Canada that care for a child with Autism Spectrum Disorder (ASD), their interaction with pediatric health care services as well as their understanding of cultural stigma and its effects. Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects approximately 1 in every 66 children in Canada (Government of Canada, 2018). The prevalence of autism is thought to be increasing in Canada and exerts a negative impact on child and family health. Although ASD cross-cuts social position and location — such as gender, race, culture and social class — there is an alarming gap in literature on the experiences of parents of visible minorities caring for children with ASD; indeed, the existing scholarship has mainly been conducted with white parents and lacks both theoretical and methodological approaches that focus on race and culture. In the broader literature, it is well documented that people of colour face racism when accessing health care services. Further, parents of visible minorities express difficulty comprehending what autism means and are confused over the heavily medicalized jargon used by health professionals. Although the existing literature has been pivotal to deepening our understanding of the barriers that parents of visible minorities with autism face, there are several notable limitations to this scholarship. The literature has not been sensitized by theoretical and methodological frameworks that focus on racial and cultural issues, such as post-colonial theory. The research has also not examined how culture influences the way that ASD is experienced by parents or the impact of stigma on parents' caregiving

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	<p>experiences. Thus, the purpose of this study is to explore the experiences of parents of visible minorities residing in Ontario that provide care to a child with autism, the impact of cultural stigma, as well as their interaction with pediatric health care services. The study purpose will be explored through a demographic questionnaire, an interview and a draw-and-write activity. The results of the study may lead to the development of a pediatric hospital-based intervention to help build social support among parents of visible minorities who care for children with ASD to assist them better in navigating the healthcare system and cultural stigma. It will also have powerful implications for parents of visible minorities caring for a child with autism, such as enhanced understanding of the effects of racism and stigma during health care encounters, as well as the impact of culture on understandings of ASD. Members of the scientific and public community may also benefit indirectly from learning new knowledge and enhancing current understanding of ASD by drawing attention to the social lives, worlds, and dilemmas to parents that face social and structural barriers.</p>
Aim of the study	<p>This study aims to understand the experiences of parents of visible minorities that care for children with ASD, while exploring the impact of cultural stigma faced by these families, and their interaction with pediatric health care services. This research will add to the tremendous gap in literature, and has the potential to support the development of a future pediatric hospital-based intervention to help build social support among parents of visible minorities who care for children with ASD, to assist them in better navigating the health care system and cultural stigma.</p>
Identify the outcome measures that will be used.	<p>The primary outcome measures of this study are to understand and become aware of (1) the experiences of parents of visible minorities that provide care to a child with ASD, (2) the impact of cultural stigma on parents of visible minorities and their child, and (3) the interactions between parents of visible minorities and pediatric health care services and its providers.</p>
Identify the participants of the study, including numbers.	<p>15 – 20 Parents / Caregivers who identify as a visible minority, caring for a child with Autism</p>
What are the risks (i.e. bloodwork) to the participants?	<p>There are no risks or harms known for participating in this study. However, the participant may feel sad or uncomfortable when talking about experiences during the interview or art activity.</p>
What are the benefits (i.e. gift card) to the participants?	<p>Participants will receive a \$20 gift card, as a token of our appreciation. Potential benefits include, the probable development of an intervention to help build social support amount visible minority parents and gain a deeper understanding of the effects of cultural stigma on parents/caregivers who are caring for a child with autism.</p>
<p>Where would you like your study advertised* (check or highlight all that apply)</p> <p>*If you would like your study to be advertised via any of the below channels, please include REB approved text with your application. Please use the other studies on our Website as a content and format guide for your text submission.</p> <p><input type="checkbox"/> Grandview's Website https://grandviewkids.ca/get-involved/research/</p> <p><input type="checkbox"/> Grandview's Facebook/Twitter https://www.facebook.com/GrandviewKids/ / @GrandviewKids</p> <p><input type="checkbox"/> Digital Signage in Waiting Rooms *send your poster as a PNG image sized to 1920 x 1080</p>	

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<input type="checkbox"/> Family Advisory Committee (closed Facebook page) <input type="checkbox"/> Grandview e-newsletter	
What is the commitment (time) of the participants/Grandview Children's Centre, and will they be reimbursed?	Participants will be involved in a two-hour interview, and a take-home art activity, which will take one hour of their time. Due to COVID-19, the interviews will happen virtually and the art activity will be mailed to the participant. However, if restrictions ease up, we will reimburse the participants for travel costs.
Identify Grandview Children's Centre staff assistance with data collection. Please include information on training/reimbursement.	Grandview Children's Centre staff will not be a part of the data collection. They will only be responsible for identifying potential participants and informing them about this study.
If Grandview Children's Centre space is required, please identify the type of space.	If COVID-19 restrictions ease up, and interviews were to happen in person, we would like a meeting room type space, to conduct the interviews.
Grandview Children's Centre would like to be sent a copy of your results (publication) that may arise from this research. Please identify a timeline for this and how you will disseminate these results to us.	The research team aims to disseminate the results through journal articles and presentations. Grandview will receive a copy of our publications, when they are made available. We are hoping to disseminate results towards the end of 2021 – 2022.
Please provide relevant background information to support this request including (if applicable): <ul style="list-style-type: none"> - Study Protocol - Invitation Letter - Recruitment Flyer - REB Approval 	We have attached the: <ul style="list-style-type: none"> - Study Protocol - Recruitment Flyer - REB Approval - Recruitment Script