



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

Project Title & Nickname	"Unmuting Marginality": Exploring the Experiences of Visible Minority Children and Youth with Autism Spectrum Disorder in the Pediatric Health Care System Through the Use of Art-Based Research
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 Ryerson University
Has the project received funding?	Funded by the Project Development Grant - Faculty of Community Services at Ryerson University
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 2020 – April 2021 – Study advertisement & Participant Recruitment October 2020 – April 2021 – Data Collection April 2021 – June 2021 – Data Analysis June 2021 – September 2021 – Study Closure & Date Dissemination/Publications/Conferences
Abstract (general abstract of the project)	Although the research is extremely scant, visible minority children and youth often describe stigmatizing health care encounters in health care environments. They often describe the health care system as lacking cultural and racial sensitivity. The purpose of this qualitative study is to explore the health care system experiences of children and youth with Autism Spectrum Disorder (ASD) who identify as visible minorities. Demographic questionnaires, interviews, as well as draw and write technique will be used as data collection tools during the study. The demographic questionnaire will include questions related to participants' age, gender, education, language and ethnicity. The interviews will include discussions on topics related to cultural stigma and interactions with healthcare services. The draw and write activity will consist of providing art supplies such as pencils or pastels to the participants. Participants will use these supplies to create images and write narratives of their lived experience as youth or child of visible minority backgrounds with ASD. A thematic and visual analysis of the data will be undertaken. By identifying the pediatric health care experiences of visible minority children and youth

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	<p>with ASD, this study will allow us to achieve several important outcomes. This study will help to better understand how these children and youth navigate complicated biomedical systems. The study might also help to develop racially and culturally sensitive interventions to enhance the healthcare experiences of visible minority children and youth with ASD. Risks of this study may include participants feeling sad or sensitive when speaking about their experiences, but researchers will inform participants that they can take a break during the interview or skip over parts they do not feel comfortable sharing. This is the second of two studies on this topic. A similar study on the parenting experiences of caregivers of visible minority children with ASD has been funded by the University of Toronto and is in progress.</p>
Aim of the study	<p>This study aims to understand the healthcare experiences of visible minority children and youth with ASD. 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 visible minority children and youth, enhance their healthcare experiences and 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 visible minority children and youth with ASD (2) the impact of cultural stigma on visible minority children and youth with ASD, and (3) the interactions between visible minority youth and children and pediatric health care services</p>
Identify the participants of the study, including numbers.	<p>15 – 20 Children/youth between the ages of 14 and 25 years old who identify as a visible minority, diagnosed with ASD</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 enhance the healthcare experiences of visible minority children and youth with ASD, to help build social support among visible minority children and youth with ASD and gain a deeper understanding of the effects of cultural stigma on this population.</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

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