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### Routing Slip

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#### Funding Opportunity

Planning and Dissemination Grant - Institute Community Support 2022-07-27

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**ResearchNet ID** 486019

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#### Applicant

Surname	Given Names	PIN
Lloyd	Meghann	178924

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#### Title

Understanding the demographics of the pediatric rehabilitation and developmental services population: Stakeholder consultations

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#### Relevant Research Area:

CIHR Institute of Health Services and Policy Research (IHSPR)

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#### Title of Priority Announcement/Funding Pools:

Planning and Dissemination Grant - Institute Community Support

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#### Linked Programs:

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**Participants Signatures**

The participants are in the following order when applicable: Principal Knowledge User, Knowledge Users, Principal Applicant and Co-Applicants, Primary Supervisor and Supervisors.

It is agreed that the general conditions governing grants and awards, as well as the role-specific responsibilities detailed in the CIHR Application Administration Guide (part 2), apply to any grant or award made pursuant to this application and hereby accepted by the participant(s).

For those assuming the role of CIHR reviewer in other funding competitions, information supplied in this application (including CV information) may be used for the purpose of informing the validation process of applications to reviewers. Accordingly, information from your application may be made available to CIHR Competition Chairs and Scientific Officers.

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**Supervisor(s) Signatures (If applicable)**

It is agreed that the general conditions governing grants and awards, as well as the role-specific responsibilities detailed in the CIHR Application Administration Guide (part 2), apply to any grant or award made pursuant to this application and are hereby accepted by the applicant's supervisor(s).

The author(s) of the Summary of the Research Project included in the candidate's application also agree that it accurately describes the training program proposed.

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**Consent to Disclosure of Personal Information**

I understand that maintaining public trust in the integrity of researchers is fundamental to building a knowledge-based society. By submitting this application or by accepting funding from CIHR, NSERC and/or SSHRC, I affirm that I have read and I agree to respect all the policies of these Agencies that are relevant to my research, including the *Tri-Agency Framework: Responsible Conduct of Research* (<http://www.rcr.ethics.gc.ca/eng/policy-politique/framework-cadre/>).

In cases of a serious breach of agency policy, the agency may publicly disclose any information relevant to the breach that is in the public interest, including my name, the nature of the breach, the institution where I was employed at the time of the breach, the institution where I am currently employed, and the recourse imposed against me.

I accept this as a condition of applying for or receiving Agency funding and I consent to such disclosure.

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Surname	Given Names	Role	Signature
Basaran	Maritza	Co-Applicant	X <i>Maritza Basaran</i>

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Institution	Faculty	Department	Date
Grandview Children's Centre (Oshawa, Ontario)		Research	July 25, 2022.

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Surname	Given Names	Role	Signature
Eickmeier	Taryn	Co-Applicant	X <i>Taryn Eickmeier</i>

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Institution	Faculty	Department	Date
Grandview Children's Centre (Oshawa, Ontario)			

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Surname	Given Names	Role	Signature
			X

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Institution	Faculty	Department	Date

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## Signature of Institution Paid

### Institution Paid Signature

It is agreed that the general conditions governing Grants and Awards, as well as the role-specific responsibilities detailed in the CIHR Application Administration Guide (part 2), apply to any grant or award made pursuant to this application and are hereby accepted by the applicant's institution or the applicant(s) employing institution(s).

**A signature is not required at institutions outside of Canada.**

If both your Program and submitting institution are using the Electronic Approval Tool on ResearchNet, a signature is not required for block 1 if the Authorized Official can bind the institution to all applicable obligations outlined the CIHR Application Administration Guide (part 2). If the Authorized Official cannot bind the institution to all applicable obligations, complete block 2.

#### 1. Signature of Authorized Official: University of Ontario Institute of Technology

Print Name: Dr. Laura Rendl, Manager, Grants and Funding Programs

Date: July 27, 2022

Signature:

X

#### 2. If the Authorized Official above cannot bind the institution to all applicable obligations outlined in the CIHR Application Administration Guide (part 2), please provide additional signatures below as required.

Print Name:

Date:

Signature:

X

Print Name:

Date:

Signature:

X

## Signature of Research Institution

### Institution Signature at Primary Location of Research (Awards Programs Only)

It is agreed that the general conditions governing Grants and Awards, as well as the role-specific responsibilities detailed in the CIHR Application Administration Guide (part 2), apply to any award made pursuant to this application and are hereby accepted by the Nominated Principal Applicant's institution where the research is to be conducted.

Signature of Authorized Official:

University of Ontario Institute of Technology

Print Name:

Date:

Signature:

X



Appl. #

## Application Details

**Funding Opportunity:**

Other: Planning and Dissemination Grants – ICS (2022-07-27)

Proposed Start Date:

2023-01-01

Proposed End Date:

2023-12-31

**Applicant:**

Surname Lloyd

Given Names Meghann

Institution

University of Ontario Institute of Technology

Faculty

Faculty of Health Sciences

Department

Telephone

905-721-8668 ext 5308

Fax

E-mail

meghann.lloyd@ontariotechu.ca

**Title:**

Understanding the demographics of the pediatric rehabilitation and developmental services population: Stakeholder consultations

**Primary location where research to be conducted:** University of Ontario Institute of Technology

Faculty: Faculty of Health Sciences

Department:

**Institution which will administer project funds (Institution Paid):**

University of Ontario Institute of Technology

**Location of proposed Activity:**

**Period of support requested:** 1 Year(s)      Month(s)

**THE FOLLOWING SECTIONS ARE NOT APPLICABLE TO ALL PROGRAMS**

**Budget section - Amounts Requested from CIHR in the First Full Year:**

Operating: 10000

Equipment: 0

Total Amount Requested: \$10000

☒ New

☐ Renewal

Funding Reference Number (FRN):

Is this application a resubmission of a previously unsuccessful new application?

☐ Yes ☒ No

Is this application a resubmission of a previously unsuccessful renewal application?

☐ Yes ☒ No FRN #:

Have you applied to this program in the last two years?

☐ Yes ☒ No

Is this a multi-center study?

☐ Yes ☐ No



### Certification Requirements

- |   |  |                                  |                                     |
|---|--|----------------------------------|-------------------------------------|
| <input type="checkbox"/> Human subjects       | <input type="checkbox"/> Human stem cells  | <input type="checkbox"/> Animals | <input type="checkbox"/> Biohazards |
| <input type="checkbox"/> Environmental Impact | <input type="checkbox"/> Containment Level |                                  |                                     |

☐ In order to carry out the proposed research in this application, an exemption from Health Canada under Section 56 of the Controlled Drugs and Substances Act is required. I agree to obtain an exemption from Health Canada to use the controlled substance for research purposes, as needed.

### Other Project Information

For statistical purposes, does this application propose research involving Indigenous peoples? ☐ Yes ☒ No

Is sex as a biological variable taken into account in the research design, methods, analysis and interpretation, and/or dissemination of findings? ☐ Yes ☒ No

Is gender as a socio-cultural factor taken into account in the research design, methods, analysis and interpretation, and/or dissemination of findings? ☒ Yes ☐ No

Please describe how sex and/or gender considerations will be integrated into your research proposal or explain why sex and/or gender are not applicable to your research proposal:

This grant is for stakeholder consultation meetings, no data is being collected on the participants of the stakeholder meetings. However, while mothers are more often the primary caregivers of children, the voice of fathers of children with disabilities is often missing in the literature. Additionally, developmental disabilities are more common in males than females, making the voice of females with developmental disabilities less common in the literature. Therefore, all efforts will be made to recruit both equal numbers of male and female participants for the parent and youth stakeholder consultation groups as they may have different feedback related to the sharing of race-based data and the planning of the next grant.



### Budget

Total Amount Requested from CIHR: \$ 10000

Total Expenses of Activity: \$ 0

### List of Attachments

1. Other - Equity, Diversity, and Inclusion (EDI) Plan (79.6 KB)
2. Other - Meeting Agenda and Participant Roles (78.1 KB)
3. Other - References (92.8 KB)
4. Other - Sex and Gender Module certificate (246.8 KB)
5. Budget Module (80.4 KB)

### Previous Applications

In the past, has an application been made to CIHR for funding to support this same Meetings, Planning and Dissemination Grant Activity?

*Provide details of all previous applications (if applicable):*

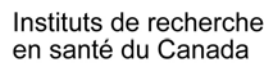
Title of Previous Activity

Competition Submitted To

Date Submitted:

Was the Application Successful?

If yes, amount received \$



RN #:486019



Appl. #  
No de la demande

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## RELEVANCE FORM | FORMULAIRE DE PERTINENCE

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### Title of Research Proposal | Titre de la proposition de recherche :

Understanding the demographics of the pediatric rehabilitation and developmental services population: Stakeholder consultations

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### Relevant Research Area | Thème de recherche pertinent :

CIHR Institute of Health Services and Policy Research  
(IHSPR)

### Title of Priority Announcement/Funding Pool |

### Titre de la demande d'Annonce de priorités/Classe de financement :

Planning and Dissemination Grant - Institute Community Support

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### Description | Description :

Reducing health inequities is a noble goal in the Canadian health and research ecosystem. To achieve this goal, at any level of the health care system, it is necessary to have accurate, disaggregated, race-based data on the population to be served. This grant addresses the strategy of embedding a health equity lens into the delivery of pediatric rehabilitation and developmental services in the Durham Region by Grandview Children's Centre; specifically seeking to understand the intersection of race and disability. Prior to the collection of this data (future research grant), we will engage with community stakeholders to inform the development of research questions, recruitment strategies, survey deployment methods, analysis of results, and knowledge translation activities. Due to the demographic composition of the stakeholder groups in this proposal, racialized parents of children with a disability and racialized youth with a disability, we will be holding meaningful engagement opportunities for groups that are underrepresented in science. The proposed series of consultation meetings closely align with the IHSPR Strategic Priorities; specifically objective 2: "Catalyze new research at the intersection of health services and policy and population health that integrates upstream prevention within health care delivery settings/approaches to improve health, health equity, and well-being, and addresses the social determinants of health." This planning grant will meaningful engage with these two intersectional (race and disability) groups (parents and youth), before writing a larger grant that will collect race-based data of the Grandview clients.





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**Other Applicants**

<b>Surname</b> Basaran	<b>Given Names</b> Maritza	<b>Role</b> Co-Applicant
<b>Institution</b> Grandview Children's Centre (Oshawa, Ontario)	<b>Department</b>	<b>Faculty</b>
<b>Surname</b> Eickmeier	<b>Given Names</b> Taryn	<b>Role</b> Co-Applicant
<b>Institution</b> Grandview Children's Centre (Oshawa, Ontario)	<b>Department</b>	<b>Faculty</b>
<b>Surname</b> Jacobs	<b>Given Names</b> Lesley	<b>Role</b> Collaborator
<b>Institution</b> University of Ontario Institute of Technology	<b>Department</b>	<b>Faculty</b>



### Descriptors \*

health equity, stakeholder consultations, race, disability, ethnicity, youth, intersectionality, community engagement, parents, pediatric rehabilitation and developmental services

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### Areas of Research \*

#### Primary

HEALTH SERVICES RESEARCH

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#### Secondary

SOCIETAL & CULTURAL DIMENSIONS OF HEALTH

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### Classification Codes \*

#### Primary

HEALTH EQUITY

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#### Secondary

HEALTH SERVICES RESEARCH

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### Themes \*

1. Health systems/services
  2. Social/Cultural/Environmental/Population Health
  3. Clinical
- 

### Suggested Institutes \*

1. Health Services and Policy Research
  2. Human Development, Child and Youth Health
-



**Suggested Peer Review Committees:**

**1<sup>st</sup>**

**2<sup>nd</sup>**

**Suggested External Referee(s)\***

Name Foster, Lorne

E-mail lfoster@yorku.ca

Area of Expertise Multiculturalism , Race and Racism, Political Economy, Youth

Name Moola, Fiona

E-mail fmoola@hollandbloorview.ca

Area of Expertise disability, race, ethnicity, youth, intersectionality

Name

E-mail

Area of Expertise

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## Lay Title and Lay Abstract

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### Lay Title:

### Lay Abstract:

Approximately 22% of Canadians identify as having a disability. The racial diversity of Canada is also increasing. There is evidence to indicate that race, and disability, both impact the quality of the care within the Canadian health care system. However, rarely is the combination of race and disability ever studied. The first step in studying this issue is to collect race-based data. Collecting race-based data is challenging and needs to be conducted in a safe, open, transparent way. Best practices indicate that engaging community stakeholders is critical to this process. Grandview Children's Centre provides pediatric rehabilitation and developmental services in the Durham Region and have partnered with Ontario Tech University for this grant. The purpose of this grant is to bring together racialized parents of children with disabilities, and youth with disabilities to hold four stakeholder consultation meetings. There are four expected outcomes from these stakeholder consultations: 1) a public report summarizing stakeholder views and preferences related to race-based data collection, use, research, dissemination, opportunities and barriers that will lead to an improved understanding of the barriers and opportunities experienced by members of the Grandview community; 2) feedback related to the approach to engage future participants in the Grandview Kids' Demographic and Inclusion Census Survey (i.e. recruitment, strategic targeting campaign ideas, incentives; questions) that will be included in the forthcoming research grant to collect this data; 3) a knowledge sharing plan to make sure the findings are communicated to the Grandview Community and, 4) a new research stakeholder advisory group to allow continuous consultations related to the collection of research data and catalyze new research ideas co-created with Grandview families.

All children's treatment centres in Ontario are committed to advancing the delivery of culturally-safe care, which leading evidence states begins with the collection of disaggregated data. Systemic mistrust and under representation by individuals experiencing an intersection of race and disability leaves a gap in existing knowledge; further, the effective means to engage clients who experience an intersectionality between race and disability in collecting data are unknown. Through funding provided by CIHR, this university-community research team will actively engage members of racialized communities with disabilities to capture the barriers, opportunities, and recommended strategies to best collect data from this under represented group to inform future service and research initiatives toward culturally-safe care.

**Overview:** In 2017, approximately 22 percent of Canadians aged 15 and older, or 6.3 million individuals, reported a disability<sup>1</sup>. Disability transcends other social divides as it includes individuals of all races, ethnicities, sexual orientations, sex, gender, religion, and socio-economic status<sup>2</sup>. Intersectionality refers to the fact that social identities based on race, gender, sex, class, sexuality and disability occur at the exact same time<sup>3-5</sup>. Historically, research has failed to acknowledge, or adequately address, the interests of individuals who experience multiple levels of bias, discrimination, or suppression<sup>6</sup>. Khan and colleagues<sup>7</sup> recommend that researchers incorporate an intersectional approach to the identification and examination of the multiple axes of inequality that intersect and shape the health of vulnerable and racialized groups in Canada.

**Discrimination is widely accepted as a determinant of health**, and in Canada there is evidence that racialized groups, and people with disabilities, experience both interpersonal and systemic discrimination<sup>5,7-10</sup>. Data from a recent survey of 5,296 Canadians from the Blackness in Canada Project, found that 70% of Black Canadians think that racism in the health care system is a serious problem. Researchers<sup>11</sup> argue that if Canadians want to seriously address racial inequities in the health systems, we need to substantially increase the quantity and quality of research on the topic. The lives of people with disabilities are shaped by racial and ethnic status, religion, language, and socioeconomic status<sup>12</sup>, and yet very little research is conducted on these intersections in the Canadian context for pediatric rehabilitation and developmental services. There is some evidence that health care professionals serving individuals with disabilities from racial and ethnic minority groups, face an even greater dilemma about serving the needs of their clients due to the multiple axis points of race and disability status<sup>12-14</sup>. Disability has historically been considered a negative health outcome rather than a population with ongoing health care needs<sup>10,15</sup> and the medical model of disability has also historically excluded the intersection of race and disability<sup>10,12,15</sup>. Additionally, the literature on disability-related barriers has largely ignored the role that race and ethnicity play in obtaining appropriate care and services<sup>16</sup>. Onyeabor<sup>14</sup> stated in 2016 that **“there is a need for more research directed at health disparity at the intersection of disability, race, and ethnicity.”**

**Grandview Children's Centre:** This planning grant capitalizes on the longstanding partnership between Ontario Tech University and Grandview Children's Centre (Grandview); they are ideal partners for this type of endeavor increasing the feasibility of the proposed work. Grandview Children's Centre is an independently operated, not-for-profit children's treatment center in the Durham Region (east of Toronto). With funding largely provided by the Ontario Ministry of Children, Community and Social Services. Grandview provides rehabilitation and developmental services to children and youth with disabilities including, but not limited to: audiology, behaviour services, developmental pediatric medical services, occupational therapy, physiotherapy, social work, and therapeutic recreation. Grandview serves more than 16,000 children and youth each

year, with an additional 11,500 children and youth waiting for services. Grandview is an early adopter of the SmartStart Hub model, which aims to ensure families receive early intervention services as early as possible<sup>17</sup>. A core principle of the SmartStart Hub model<sup>17</sup> is to be “equitable and culturally safe.” As such, Hubs are “to promote respectful engagement that recognizes and strives to address power imbalances between service providers and families” (p. 15). Within the eight municipalities that make up of the Durham Region, 27.1% of adults identified as a visible minority in 2016<sup>18</sup> and 24% were immigrants<sup>19</sup>. The Town of Ajax has also declared itself to be a sanctuary city, supporting undocumented or precarious status residents full access to local services, supporting their path to citizenship<sup>20</sup>. With an ever-increasing population, the demand for Grandview services continues to grow, putting great pressure on the need to better understand the changing demographics, cultural needs, and implement a family-led approach to culturally safe care. Culturally safe care is defined as an outcome, based on respectful engagement, that recognizes and strives to address power imbalances inherent in the healthcare system<sup>21</sup>.

**The Problem: A need for race-based data:** Social determinants of health, such as income, immigration, or educational status, are often examined in the context of the Canadian health care system; however, the influence of race or racism on health has not been as extensively studied in Canada<sup>11</sup> as it has in the United States<sup>22</sup>. Evidence is clear that Canada’s “visible minority” population is rapidly increasing<sup>7</sup>, and valid and reliable data are fundamental building blocks for identifying differences in care, and in developing targeted interventions to improve the quality of care<sup>5,23</sup>. **The first step is to collect disaggregated race-based data.** Baker and colleagues<sup>24</sup> found that 80% of those surveyed either somewhat or strongly agreed that health care providers should collect information on patient’s or client’s race and/or ethnicity. Importantly, self-reported data, directly from the individuals, is more accurate than observational categorization<sup>23</sup>. There is a critical need to address this lack of disaggregated race-based data in pediatric rehabilitation and developmental services to truly provide equitable, culturally safe care<sup>5</sup>.

Collecting race-based data is important<sup>25</sup>, but not without its challenges. Baker and colleagues<sup>24</sup> found that while the vast majority of patients feel that health care providers should collect information about race and/or ethnicity; many feel uncomfortable giving this information, especially among visible minority groups. However, they also found that health care providers can increase clients’ comfort levels by *clearly explaining that the data will be used to monitor quality of care*<sup>24</sup>. Within the therapeutic relationship, there is an element of unavoidable vulnerability and trust where the client is at a disadvantage before clinicians<sup>23</sup>. Racial, ethnic, cultural, and linguistic discordance between patients and providers can increase the potential for misunderstanding, distrust, and ability to communicate effectively<sup>23</sup>. **It is therefore vital to collect information about clients’ race, and ethnicity, in a manner that does not erode trust or put the therapeutic relationship in jeopardy.** Similarly, there are challenges in collecting accurate data on disability populations<sup>26</sup>. Often questions are written using stigmatizing words, reference suffering, or use inaccurate labels; and all of this is complicated by the temporal and cultural interpretations of what “disability” means<sup>26</sup>. Therefore, it is absolutely critical that before embarking on a demographic census, stakeholders are engaged to inform, shape, and guide the process<sup>5</sup>.

**Community engagement is essential:** The Canadian Institute for Health Information (CIHI)<sup>5</sup> acknowledges that there many benefits to collecting, measuring and analyzing race-based

identity data, but that there are also risks and barriers to assess and mitigate. Risks and barriers include potential discomfort, previous experiences in health care that have resulted in distrust, fear of self-identifying, and the potential for stigma or discrimination to lead to unequal care or treatment<sup>7-10</sup>. Prioritizing safe and appropriate collection and use of this data is an essential step in identifying and addressing inequities in health and health care<sup>5</sup>. CIHI states<sup>5</sup> that “*community engagement is best practice and foundational to the respectful collection and appropriate use of race-based and Indigenous identity data in health care*” (p. 12). Community members (people with lived experience and local knowledge), specifically people who experience the intersection of race and disability in the context of this grant, are more knowledgeable about the health priorities and broader social, political, economic and historical context of their communities than researchers. Race-based data collection needs to be open, transparent, and reduce the risk of harm<sup>5</sup>. Openness and transparency are key to building trust with communities and mitigating the risk of doing harm<sup>5</sup>.

We know we need to collect disaggregated race-based data as a first step in ensuring the delivery of culturally safe pediatric rehabilitation and developmental services at Grandview; the purpose of this grant is to engage in stakeholder consultations to address how might we effectively engage marginalized communities at the intersection of race and disability.

## Objectives

1. Consult and engage with racialized parents of children and youth with disabilities (n=30) regarding the barriers and opportunities, from their perspectives, in sharing race-based identity data to inform culturally safe care at Grandview.
2. Consult and engage with racialized youth with disabilities (n=15), regarding the barriers and opportunities, from their perspectives, in sharing race-based identity data.
3. Facilitate partnerships between researchers and key stakeholders for continuous consultations re: collection, use, research, and dissemination of race-based data (beyond the life of this grant).

**Project Activities:** To achieve Objectives 1 and 2, we will employ a mainstream approach to engagement by holding four stakeholder consultation meetings: two meetings (one online, one in-person) for racialized parents of children with disabilities and two meetings (one online, one in-person) with racialized youth with disabilities. The reason for the hybrid approach is to increase the accessibility and inclusion options. While in-person meetings are important for relationship building, the establishment of trust, reciprocal interactions, and flow of conversation, the COVID pandemic has highlighted the advantages of also holding virtual meetings. These advantages include, but are not limited to, reducing the risk of COVID for people who are at elevated risk, the ease of live closed-captioning, the ability to easily hire and include an ASL translator if needed, and to eliminate the travel burden for parents who live in rural and remote areas. All parents and youth will be given the choice of which meeting they would like to attend.

**All participants will be current Grandview families and/or clients.** Grandview has very strong relationships with the families they serve, there is a significant level of mutual trust; therefore, Grandview's role is critical to the success of this grant in that families will be more likely to engage in these meetings when the invitation comes from their children's trusted care provider. In addition, to achieve Objective 3, members of these groups will be invited to form the community advisory committee specifically for research to catalyze planning, consultation, research and dissemination work beyond the present grant. To this end, this advisory committee will become a platform for engagement in ongoing consultations with the research team to 1)

govern the application to the next tri-council research grant to conduct the work of collecting the disaggregated race-based data from Grandview families; 2) establish community-based recommendations on how to recruit, collect, analyze, and report race-based data to parents and youth experiencing an intersection of race and disability; and 3) facilitate a co-designed knowledge mobilization plan to transparently communicate the findings of the forthcoming Census Survey. The proposed series of consultation meetings closely align with the IHSPR Strategic Priorities; specifically, objective 2: “*Catalyze new research at the intersection of health services and policy and population health that integrates upstream prevention within health care delivery settings/approaches to improve health, health equity, and well-being, and addresses the social determinants of health.*”

### Project Timeline

Activity	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Hire EDI facilitator/consultant												
Meeting Preparation												
Recruit meeting Participants												
Hold Parent meetings												
Hold Youth meetings												
Knowledge Translation Activities (public report, academic conferences)												
Grant preparation and submission												

**Expected Outcomes:** There are 4 expected outcomes from these stakeholder consultations: 1) a public report summarizing de-identified stakeholder views and preferences related to the barriers, opportunities and preferred strategies to race-based data collection experienced by members of the Grandview community experiencing an intersection of race and disability; 2) a community-informed methodology to recruit, collect, analyze and report race-based data from the Grandview community as part of a tri-council research grant application; 3) a co-designed knowledge mobilization plan to transparently communicate the findings of the forthcoming Census Survey and ways in which data will be used to inform the strategic priorities of Grandview Kids; and 4) creation of a new community advisory committee to enable on-going consultations to inform and govern the application of a tri-council research grant and inform future culturally-safe care practices. Findings will be disseminated via publicly available reports, and local interest groups such as the Durham Best Start Network and the Durham Child and Youth Planning Network. Grandview will engage their Family Advisory Council and their Youth Advisory Council, and their networks, to facilitate the dissemination of the results of the stakeholder meetings. Grandview and Ontario Tech’s social media and websites will also be used to engage local stakeholders in addition to presenting the results at academic meetings.

**Research Team: Meghann Lloyd, PhD:** Dr. Lloyd’s research focuses on rehabilitation sciences, adapted physical activity, and the health of people with intellectual and developmental disabilities. Dr. Lloyd is also a Research Associate at Grandview Children’s Centre. **Taryn Eickmeier, PhD:** Dr. Eickmeier’s expertise includes qualitative inquiry, integrated knowledge translation, and the development of meaningful partnerships between academic, non-profit, and community members. **Maritza Basaran, MSc:** Ms. Basaran is a Research Coordinator and Knowledge Broker at Grandview in addition to her clinical role as a behaviour technician. **Les Jacobs, PhD:** Dr. Jacobs is a leading international expert in applications of data science to research questions involving equality of opportunity, human rights policy, and access to justice; health and human rights, and the collection of race-based data. Dr Lloyd and Dr Eickmeier will co-lead the activities to achieve the goals of this grant, assisted by Ms Basaran. Dr. Jacobs will consult on the interpretation of the results of the consultations that will be used to inform the next larger research grant.



**Canadian Institutes of Health Research  
Institute of Health Services and Policy Research  
ICES**  
2075 Bayview Avenue  
Toronto, ON M4N 3M5

July 20, 2022

Dear Review Board Members,

Grandview Children's Centre is proud to partner with Ontario Tech University to deliver the application entitled: "Understanding the demographics of the pediatric rehabilitation and developmental services population: Stakeholder consultations" for consideration for the CIHR Planning Grant under the Institute of Health Services and Policy Research (IHSPR).

The proposed series of consultation meetings closely align within the IHSPR Strategic Priority 1: "Accelerate the discovery of innovations that transform health care delivery systems to achieve the Quadruple Aim and improve health equity for all," specifically, objective 2: "Catalyze new research at the intersection of health services and policy and population health that integrates upstream prevention within health care delivery settings/approaches to improve health, health equity and well-being, and addresses the social determinants of health."

As an active member of the Ontario Health Team – Durham, Grandview actively contributes to the assessment and evaluation of the Quadruple Aim with a system-wide paediatric lens. As related to the proposed work, the commitment to exploring the client and caregiver experience is of utmost importance to making improvements to our outpatient and community-based services. Furthermore, our existing strategic plan, Building on Excellence, aims to promote wellness and diversity by advancing research and evidence-based practice. Our Board of Trustees have endorsed our newly established Equity, Diversity and Inclusion Committee and the Ontario Ministry of Children, Community and Social Services has recognized our agency as an early adopter of SmartStart Hubs.

We have incorporated our commitment to equity, diversity and inclusion into the SmartStart Hub, which aims to provide early intervention services to children as soon as possible. Through our provision of services, we aim to provide culturally-safe care; a means by which power imbalances are thoughtfully addressed to sustain an environment that is free of racism and discrimination. The proposed consultation meetings will help us identify ways in which our marginalized community members wish to share and engage in the collection of race-based data, which will further our abilities to design, deliver, and evaluate culturally safe care.

Grandview's role will include:

**Every child and youth living life at their full potential.**

- Governance of the project as part of the research team alongside OntarioTech University.
- Advertising and recruitment of an equity, diversity and inclusion facilitator.
- Advertising and recruitment of parents/caregivers and youth within the ~27,5000 families accessing or waiting to access our services.
- Observers in the consultation meetings.
- Advisors on the interpretation of results and conclusions.
- Promotion of end-of-grant knowledge mobilization materials, such as posting the consultation report on our website and creating opportunities for presentation of results at local pediatric network meetings.

Grandview will provide in-kind contributions via:

- Staffing to support recruitment, note-taking, reporting and governance (Senior leader, Research Coordinator and Knowledge Broker, Communications and Marketing Manager, Privacy Officer, Family Engagement Team, Human Resources).
- Recruitment and strategic communications (Social media, print, web advertisements including graphic design).
- Technology and software (Zoom licenses, MS Office suite, secure communication with potential participants).

Grandview intends to use the information to inform the next tri-council research grant alongside OntarioTech University to conduct a Diversity Census and Inclusion Survey with families accessing and waiting to access service. Thereafter, we intend to continue to support the community advisory committee to help inform culturally-safe practices as part of daily operations in-centre and in the community. Ultimately, we hope that this work will be spread across all Canadian children's treatment centres to inform emerging best practices, something that currently does not yet exist in our sector.

Thank you for your time and consideration,



Lorraine Sunstrum-Mann  
Chief Executive Officer  
Grandview Children's Centre

## Equity, Diversity, and Inclusion (EDI) Plan

In the planning of this grant, we acknowledge that increasing the participation of under-represented groups in co-design activities can result in novel solutions and ensure study outcomes do not further promote inequities in care. First, we would like to acknowledge that Indigenous communities also face barriers, biases, and inequities when accessing pediatric rehabilitation and developmental services. However, the research team cannot authentically conduct research with Indigenous communities without an established partnership, lead by our local Indigenous partners; this work is ongoing, separately. While we will not exclude participants identifying as Indigenous from the stakeholder consultations, without an existing relationship and member of our research team with Indigenous heritage, we will not *target* Indigenous community members. The following strategies will be used within our plan to promote equitable principles of codesign that are focused on equal power distribution, building of capacity and capability, building relationships, and promoting active participation.

**Self-Reflection:** Reflecting on our own sociocultural context, knowledge, and biases will better enable our team to interact with participants effectively and interpret data accurately. In this reflection we will consider what we need to be aware of, and how our team might be perceived by participants, as well as how we might perceive them.

**Expert EDI Facilitator:** We acknowledge the existence of system inequities including discrimination and oppression limiting participation in engagement processes. Therefore, we will hire highly a trained EDI facilitator who has the necessary skills to identify and address perceived and established power dynamics, oppression, and discrimination related to EDI in the Canadian context.

**Pre-Meeting Survey:** We will ask participants what their English proficiency and comfort levels are and what types of support they may need before the session. This will help to determine how to form groups and plan activities. We can also learn about any special accommodations they may need (e.g. translation support), restrictions based on cultures and beliefs, or physical accommodations.

**Consideration of Communication Barriers:** Meeting activities will include simple instructions paired with visuals and examples, when possible. In addition, pre-populated cards (or pre-typed messages for virtual participants) with useful phrases for cross-linguistic conversations will be shared with all participants (e.g. “Please speak more slowly, “Please say that again”).

**Inclusion of Non-Verbal Activities:** To reduce barriers to participation related to language, various modalities will be prepared to allow participants to engage in activities in a way they are most comfortable with. Modalities include visuals where participants will be given the choice to find their own images (e.g. Google images) or select from an array of images provided by the research team. Drawings may also be used throughout the session giving participants the opportunity to share their experiences in a way that is not limited by vocabulary. It is important to note that participants will be offered a choice.

**Compensation for Time:** All families will be compensated for their time, as well as reimbursed for travel-related expenses. Additionally, we will provide child-minding for the one parent group who participate in-person, with trained recreation assistants. These strategies are being employed to fairly, and adequately honour the time, expertise, and experiences of the participants.

**Meeting Agenda**

	Topic	Lead	Description	Time
1	Welcome and Introduction	EDI Facilitator	<ul style="list-style-type: none"> <li>Meeting guidelines and confidentiality</li> <li>Overview of the purpose of meeting and agenda – <i>setting the stage for why disaggregated race-based data is needed and how it would be used</i></li> </ul>	6:00 p.m.
2	Icebreaker Activity	All	<ul style="list-style-type: none"> <li>Participants introduce themselves and share an item or picture that is meaningful to culture and/or identity</li> <li>Explain that having common experiences and hearing personal stories builds rapport and makes participants more comfortable engaging with each other and facilitators</li> </ul>	6:10 p.m.
3	Storytelling Presentation	EDI Champions	<ul style="list-style-type: none"> <li>A panel composed of individuals with lived experience will share the value of collecting race-based data and the importance of incorporating culture into care</li> </ul>	6:30 p.m.
4	Break			7:00 p.m.
5	Current State Journey Mapping Activity	All	<ul style="list-style-type: none"> <li>Small group activity where participants will develop visual representations of experiences in the journey of care</li> </ul>	7:10 p.m.
6	Debrief	All	<ul style="list-style-type: none"> <li>Review of the identified existing challenges and opportunities</li> <li>Explain how these experiences can be used to inform future actionable items</li> </ul>	7:40 p.m.
7	Break			7:50 p.m.
8	Ideal State Idea Generation Activity	All	<ul style="list-style-type: none"> <li>Interactive activity that will ask participants to answer questions about how they would want to engage in race-based data collection (e.g. what supports might they require?, what would be the preferred format?)</li> <li>Participants may pass around their generated ideas or swap ideas and add to others' ideas</li> </ul>	8:00 p.m.
9	Priority Rating	All	<ul style="list-style-type: none"> <li>To help inform actionable next steps, participants will rank what items are most important to them</li> </ul>	8:30 p.m.
10	Wrap-up and Reflection	EDI Facilitator	<ul style="list-style-type: none"> <li>The closing discussion will give participants the opportunity to reflect and comment on the meeting experience and generated concepts.</li> </ul>	8:45 p.m.

## **Participant Roles and Description**

**Facilitator:** A highly trained, EDI expert facilitator with expertise in co-design and EDI will lead the meetings and guide participants through journey mapping, and priority setting activities. We acknowledge the existence of system inequities including discrimination and oppression limiting participation in engagement processes. Therefore, the facilitator will have the necessary skills to identify and address perceived and established power dynamics, oppression, and discrimination.

**Note Takers:** Their primary role will be in data collection during the meetings. The research team commits to recruiting, and retaining, a racially diverse group of note takers to engage in this research project. Note takers will be students from Ontario Tech University. While EDI data at universities is limited, the 2020 National Survey of Student Engagement asked students to select all ethno-cultural groups that apply to them. At Ontario Tech, 55% of respondents identified as being a visible minority. An internal survey of applicants for 2021 revealed that 23% of first choice applicants were immigrants, with approximately 10% of applicants self-identifying as having a disability, and current data indicates that approximately 85% of Ontario Tech students are receiving some sort of financial assistance to attend school (e.g. loans, grants, OSAP, NSLSC etc.). Note takers will be provided with research opportunities that integrate race data collection and will also learn why disaggregated race data is important and valuable, how to think through benchmarks for analysis, threshold levels for racial disparities and disproportionalities, as well as broader health research on racial disparities. Experiential learning and the opportunity for learners to engage with community partners is a core value of the research team.

**EDI Champions:** A group of four to five, both adults and youth with lived experience receiving services as a racialized community member. Their main role will be to prepare and deliver a brief presentation that will review the value and need for research directed at health disparity at the intersection of disability, race, and ethnicity. The champions will explain in plain language why this work is important to them and offer perspectives that are driven by their own priorities of receiving culturally-safe care. EDI Champions will also consult on recruitment strategies and knowledge mobilization activities and participate in all meeting activities.

**Research Team:** Team comprised of leaders in design/evaluation of outcome measures and qualitative methodology from Ontario Tech University and Grandview Kids. The team will contribute jointly to the planning of the meeting and will participate in recruitment, knowledge synthesis, and knowledge sharing. The research team will be responsible and accountable for the completion of project milestones in a manner that is ethical, reflective of the shared EDI plan. Ontario Tech will be responsible for management of data and financial administration.

**Parents:** A group of 30 parents of racialized parents of children and youth with disabilities will be recruited. Their primary role will be to attend a 180-minute meeting and share their perspectives relating to barriers and opportunities in sharing race-based identity. Parents will also be asked to share their perspectives on best practices for the recruitment of future participants, how to ask questions related to the intersection of race and disability, and how they would like to be consulted to prepare for the next research grant.

**Youth:** A group of 15 youth of racialized youth with disabilities. Their primary role will be to attend a 180-minute meeting and share their perspectives regarding the barriers and opportunities in sharing race-based identity data and best practices for the next research grant. Parent and youth participants will offer a diversity of perspective and representation of age, culture, disability, education, ethnicity, gender expression, gender identity, immigration and newcomer status, language, neurodiversity, parental status/representation, place of origin, religion, race, sexual orientation and socio-economic status.

## REFERENCES

1. Morris SP, Fawcett G, Brisebois L, Hughes J. A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017. In: Statistics Canada= Statistique Canada; 2018.
2. McDonald KE, Keys CB, Balcazar FE. Disability, race/ethnicity and gender: Themes of cultural oppression, acts of individual resistance. *American Journal of Community Psychology*. 2007;39(1):145-161.
3. Purdie-Vaughns V, Eibach RP. Intersectional invisibility: The distinctive advantages and disadvantages of multiple subordinate-group identities. *Sex roles*. 2008;59(5):377-391.
4. Crenshaw K. Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *u Chi Legal f*. 1989:139.
5. Canadian Institute for Health Information. Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada. In. Ottawa, ON: CIHI; 2022.
6. Cole ER. Intersectionality and research in psychology. *American psychologist*. 2009;64(3):170.
7. Khan MM, Kobayashi K, Vang ZM, Lee SM. Are visible minorities “invisible” in Canadian health data and research? A scoping review. *International Journal of Migration, Health and Social Care*. 2017.
8. Thompson E, Edjoc R, Atchessi N, Striha M, Gabrani-Juma I, Dawson T. COVID-19 race data collection in Canada. *Can Commun Dis Rep*. 2021;47(7/8):300-304.
9. Gajaria A, Guzder J, Rasasingham R. What’s race got to do with it? A proposed framework to address racism’s impacts on child and adolescent mental health in Canada. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*. 2021;30(2):131.
10. Goode TD, Carter-Pokras OD, Horner-Johnson W, Yee S. Parallel tracks: Reflections on the need for collaborative health disparities research on race/ethnicity and disability. *Medical care*. 2014;52(10 0 3):S3.
11. Datta G, Siddiqi A, Lofters A. Transforming race-based health research in Canada. *CMAJ*. 2021;193(3):E99-E100.
12. Maroto M, Pettinicchio D, Patterson AC. Hierarchies of categorical disadvantage: Economic insecurity at the intersection of disability, gender, and race. *Gender & Society*. 2019;33(1):64-93.
13. Barton J, Trupin L, Schillinger D, et al. Racial and ethnic disparities in disease activity and function among persons with rheumatoid arthritis from university-affiliated clinics. *Arthritis care & research*. 2011;63(9):1238-1246.
14. Onyeabor S. Addressing health disparities at the intersection of disability, race, and ethnicity: The need for culturally and linguistically appropriate training for healthcare professionals. *Journal of racial and ethnic health disparities*. 2016;3(3):389-393.
15. Shaw LR, Chan F, McMahon BT. Intersectionality and disability harassment: The interactive effects of disability, race, age, and gender. *Rehabilitation Counseling Bulletin*. 2012;55(2):82-91.
16. Peterson-Besse JJ, Walsh ES, Horner-Johnson W, Goode TD, Wheeler B. Barriers to health care among people with disabilities who are members of underserved racial/ethnic groups: a scoping review of the literature. *Medical care*. 2014:S51-S63.

17. Ministry of Children CaSS. SmartStart Hubs connecting families with child development: Policy and Practice Guidelines. In. Ontario: Government of Ontario; 2022.
18. Durham Region. *Durham Region Profile: Demographic and Socio-economic Data*. Ontario2020.
19. Durham Region. *Durham Immigration and Inclusion Community Plan 2020-2024*. Ontario2020.
20. City of Ajax. Ajax Council officially declares Town of Ajax a Sanctuary City. <https://www.ajax.ca/en/ajax-council-officially-declares-town-of-ajax-a-sanctuary-city.aspx>. Published 2017. Accessed.
21. Provincial Health Services Authority. *COVID-19: Maintaining a Safe and Inclusive Culture*. British Columbia2020.
22. Centers for Disease Control Prevention. Racial/ethnic disparities in self-rated health status among adults with and without disabilities--United States, 2004-2006. *MMWR Morbidity and mortality weekly report*. 2008;57(39):1069-1073.
23. Hasnain-Wynia R, Baker DW. Obtaining data on patient race, ethnicity, and primary language in health care organizations: current challenges and proposed solutions. *Health services research*. 2006;41(4p1):1501-1518.
24. Baker DW, Cameron KA, Feinglass J, et al. Patients' attitudes toward health care providers collecting information about their race and ethnicity. *Journal of General Internal Medicine*. 2005;20(10):895-900.
25. Anti-Racism Act, S.O. 2017, c. 15, (2017).
26. Pettinicchio D, Maroto M. Who Counts? Measuring Disability Cross-Nationally in Census Data. *Journal of Survey Statistics and Methodology*. 2021;9(2):257-284.

This is to certify that

**Meghann Lloyd**

has successfully completed the CIHR Institute of Gender and Health Core Competency Module for Sex and Gender in Primary Data Collection with Human Participants.

A handwritten signature in black ink that reads "Cara Tannenbaum". The signature is written in a cursive style and is positioned above a horizontal line.

**Cara Tannenbaum, MD, MSc**  
Scientific Director  
CIHR Institute of Gender & Health



# Budget

## Budget Module: Funds requested

Item	Amount	Justification
<b>Personnel</b>		
EDI Expert Facilitator	\$6,300	Hiring an external facilitator is part of our inclusive EDI strategy to provide our stakeholder consultations with resources they need to fully participate by building expertise and capacity such as engaging in dialogue. An expert EDI facilitator has the skills, background and expertise to achieve the goals of these stakeholder consultations while also disrupting the power imbalance between families and Grandview and Ontario Tech. An expert EDI facilitator with lived-experience is absolutely critical to the success of this grant and is reflected in the budget allocation. The EDI facilitator will also contribute to finalizing the agenda with identifying key activities to achieve the objectives of this grant in advance and will prepare a report based on the content of the 4 meetings.
<b>Meeting Expenses</b>		
Room rental	\$160	To increase access for community members in Durham Region, a neutral location for the in-person groups was selected within 50 km of high racialized communities according to regional demographic data.
Food and beverages	\$300	Light refreshments will be provided for two in-person stakeholder consultations; any children will also be provided a snack while being cared for while their parents are engaging in our meetings.
Meeting Materials	\$255	For study related office supplies and meeting materials for the in-person focus groups (e.g. pens, notebooks, printing).
<b>Other Expenses</b>		
Honoraria (n=45)	\$2,250	In accordance with our institution's policies and processes, and our inclusive EDI strategy, all stakeholder group members will receive \$50 (cash and non-cash options available) for their participation in a 180-minute discussion. We recognized the value of our stakeholders' lived experiences, their time, and their expertise and therefore are budgeting to compensate them. Providing compensation, also serves to help reach underrepresented research groups.
Mileage to in-person focus group	\$575	Mileage for in-person focus group participants. Average 50km round journey @ \$0.50 per km x 23. It is understood that transportation can be a barrier to participating in research, therefore providing compensation to travel to participate is warranted. Online options are also provided for those who are not able to travel.
Child Minding	\$160	To increase access, and the ability for community members to participate in our study, child minding will be provided to caregiver participants during the in-person stakeholder consultations. Grandview therapeutic recreation staff (\$40/hr) will be providing this service due to their knowledge and training in working with children/youth with disabilities
<b>Total</b>	<b>\$10,000</b>	

## Budget

### Budget Module: In-Kind contributions

Name of Organization	Cash	In-Kind
Grandview Kids	\$0	\$4,200.00
Total		<b>\$4,200.00</b>

#### Description:

Grandview Kids is committed to supporting this project and will contribute to both the research and knowledge sharing activities. In kind:

- Recruitment support (i.e. Research Assistant) = \$500
- Staffing to support reporting and governance (Senior leader, Research Coordinator and Knowledge Broker, Privacy Officer, Family Engagement Team, Human Resources= \$2000
- Strategic communications (e.g. Social media, print, web advertisements, graphic design) = \$1500
- Technology and software (Zoom licenses, MS Office suite, secure communication with potential participants) = \$200

Name of Organization	Cash	In-Kind
Ontario Tech	\$0	\$ 3300
Total		<b>\$ 3300</b>

#### Description:

Ontario Tech University is committed to supporting this project and will contribute to both the research and knowledge sharing activities. In kind:

- Recruitment support (i.e. Research Assistant/grad student) = \$500
- Note taking (12 hours x 2 people) = \$600
- Technology and software (e.g. zoom licenses, google meets) = \$200
- Grant Administration \$1000
- Strategic communications (e.g. dissemination of report to partners) = \$1000

## Applicant profile

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Name: Maritza Basaran, MSc

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Title/role: Research Coordinator and Knowledge Broker

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Affiliation/community: Grandview Kids

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Areas of expertise/knowledge and/or education: knowledge translation, autism spectrum disorder, family engagement, disability, co-design, behaviour analysis, equity, diversity and inclusion.

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### A. Personal Statement

I am an early career investigator with over five years of experience working within multidisciplinary research teams as a clinician, family partner, and researcher. I am a Peruvian-Canadian mother to a child with autism spectrum disorder (ASD) and skilled in supporting research that works to increase opportunities for patient and family engagement in research and improve access to culturally-safe, quality care for racialized families.

In my professional role as a Research Coordinator and Knowledge Broker, I support research teams in the development, implementation, and evaluation of knowledge translation (KT) products and strategies. I am also a member of the Durham Region Research and Knowledge Mobilization Sub-committee where I engage with KT specialists in the community and support community-based knowledge exchange. To strengthen my knowledge in KT, I have completed the Knowledge Translation Professional Certificate program offered through the Learning Institute at The Hospital for Sick Children. With this training, I have learned to approach complex problems through an integrated lens, thinking of knowledge users prior to planning.

Complimentary to my professional work, as a parent with lived experience, I bring great value to connecting with caregivers resulting in prompt uptake. Through my experience and training in the Family Engagement in Research Course offered through CanChild and McMaster University, I understand the psychology behind collaborative relationships and have learned strategies to build relationships with potential family partners.

Due to the combination of my professional and lived experience, I am an asset to research teams that aim to partner with community members to improve the quality of health research and services. As co-chair of the Equity, Diversity and Inclusion Committee I continue to be a champion in creating engagement opportunities that meet the needs of minority groups, ultimately resulting in outcomes that are truly meaningful and useful to a broader range of knowledge users.

## B. Positions and Honours

### Employment

- **Research Coordinator and Knowledge Broker**, Grandview Kids, (November 2021 – Present)
- **Co-Chair of Equity, Diversity and Inclusion Committee**, Grandview Kids, (September 2021 – Present)
- **Research Assistant**, Grandview Kids, (September 2020 – November 2021)
- **Family Leader**, Holland Bloorview Kids Rehabilitation Hospital, (February 2018 – Present)
- **Autism Therapy Assistant**, Grandview Kids, (September 2019 – November 2021)

### Achievements

#### Academic:

- **Master of Science in Applied Behaviour Analysis**, Queen's University, Belfast (2020-2022)
- **Bachelor of Arts (Honours) in Psychology, Health Science, and English**, University of Toronto, (2008-2012)

#### Professional:

- **Knowledge Translation Professional Certificate**, Continuing Professional Development, University of Toronto's Faculty of Medicine, The Hospital for Sick Children, (July, 2022)
- **Family Engagement in Research Certificate**, Continuing Education, McMaster University, Can Child, (February, 2021)

## C. Contributions to Knowledge Creation, Knowledge Sharing, and/or Knowledge Translation

**Knowledge Translation:** Assisted in developing a KT plan for FEED ASD. Participated in media interviews and development of website content (2021)

**Community-based Knowledge Mobilization Committee Member:** Build capacity for research and knowledge exchange in post-secondary institutions and agencies serving children, youth and families in Durham Region by developing and supporting community-driven research frameworks and fostering the development of collaborative partnerships

**Invited Speaker:** Lead a keynote presentation 'Learning from Lived Experience to Enhance Family Engagement in Research', BRI Trainee Professional Development Day, (2021) Bloorview Research Institute. Lead a presentation 'Building stronger families through family engagement in research, (2021) Developmental Paediatrics Rounds, Grandview Kids.

**Knowledge Translation Event Organizer:** Lead the planning and organization of Grandview Kids Research Day (2021). Invited 20 speakers to showcase knowledge that has impacted children's treatment centres in Ontario.

**Program Evaluator:** Assisted in the development of a program evaluation plan for the Durham Complex Care Program and supported the dissemination of results (2021).

## D. Other Relevant Information

- [Project ScreenPlay – Expanding its reach](#): This is a project that received funding from the Centre for Leadership in Innovation at Holland Bloorview Kids Rehabilitation Hospital. ScreenPlay was designed to be maximally accessible to people of all abilities and consults with clients and their families were essential to designing an effective solution for inclusive pediatric healthcare waiting spaces.
- [Student Project – KT Road Map](#): This visual integrated interactive KT road map was co-designed with members from Grandview Kids' Family Engagement Team. It was designed to allow families and patient partners to explore various aspects of research that might be relevant to them when deciding if and when they may become involved as a research partner. It is a tool that can be adapted and changed as knowledge changes over time. It incorporates previous KT tools to support families as they explore their role in research both now and in the future.
- ['Learning to eat at home': a collaborative study](#): ASD Feed-Ed has its origins in Project LeAH ("Learning to Eat At Home"), a Bloorview Research Institute (BRI) study that tested a multidisciplinary telehealth approach with 15 preschoolers with ASD and their families. As a family partner in this study, I was actively engaged in several dissemination strategies including plain language articles in hospital newsletters and television broadcasts.
- [A Lived-Experience Story – Games that make therapy fun](#): Bloom magazine was created to bring together the expertise of families and professionals in clinical care, research and education. Bloom blog unites parents of children with disabilities and clinicians in 146 countries in an international community of support. The following interview describes how my lived experience of being a sibling caregiver to my adult brother with complex needs informed and influenced my research work.