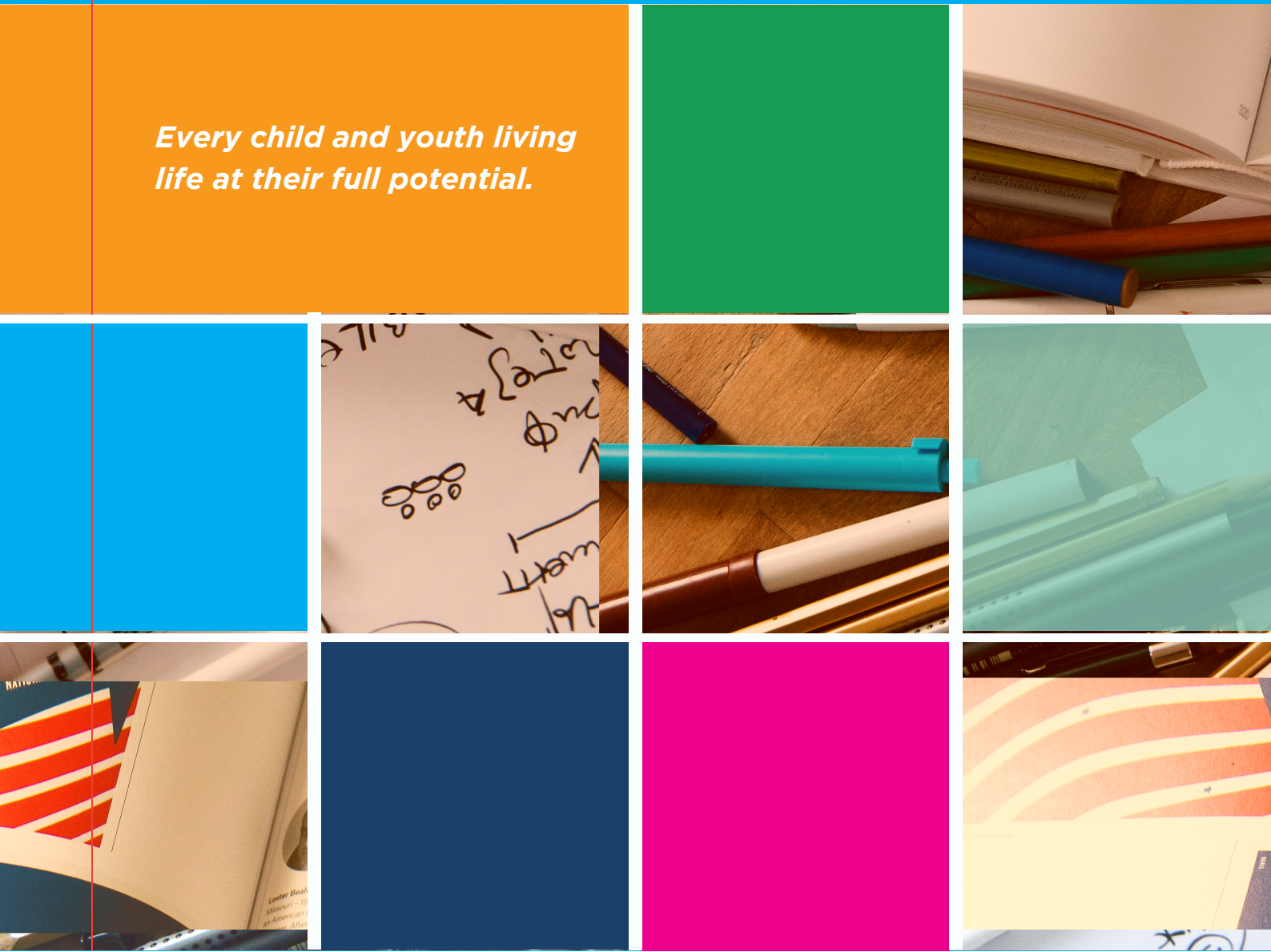




Research & Innovation

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



A message from the Executive Lead

Building on a decade of active contribution to disability studies and rehabilitation sciences, I am pleased to take on the position of Executive Lead of Research, Innovation and Knowledge Mobilization with Grandview Kids.

Much of our historic success comes from the dedication of our Medical Services Team, led by Dr. Carolyn Hunt. Together with partners at academic and healthcare institutions, Dr. Hunt has set the foundation from which this new portfolio will thrive. This year, we focused on exploring the possibilities, building on the past, and placing our sights on the future.

Throughout the pages of this annual portfolio, you'll read about our contributions and achievements. Hereafter, we are looking forward to our continued collaboration with clients, caregivers, Grandview graduates, members of Team Grandview and our academic and community partners.

Taryn Eickmeier, Ph.D.

*Executive Lead
Research, Innovation and
Knowledge Mobilization*



Research & Innovation at Grandview Kids

 <https://grandviewkids.ca/research/>

Collaborate with Grandview Kids

If you would like Grandview Kids to promote your research project, please complete the **Grandview Kids Application for Approval of a Research Study**. Please ensure you have received approval from your local Research Ethics Board prior to submitting your request. Requests are reviewed monthly by the Research and Innovation Committee. Questions can be directed to research@grandviewkids.ca.

Share your research and innovation with Team Grandview

Team Grandview hosts a monthly Lunch and Learn or Journal Club. If you are interested in presenting your research to our interdisciplinary clinical and medical teams, please get in touch with research@grandviewkids.ca.

Promote your innovation to Team Grandview

If you are a start-up or vendor looking to share your invention, innovation or product with members of our clinical and medical teams, please complete the **Innovation Application form**. Requests are reviewed monthly by the Research and Innovation Team, with demonstrations available in-person or virtually.



Contents

Strategic goals	01
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Defining our purpose	02
----------------------	----

The team	03
----------	----

Research and Innovation Committee	04
-----------------------------------	----

Year in review	05
----------------	----

Research	06
----------	----

Innovation	10
------------	----

Knowledge mobilization	12
------------------------	----

Strategic goals 2018-23

Advance research and evidence-based practice

1. Increase the availability of research evidence and its disciplined use to inform point-of-care decision making
2. Identify, trial and assess innovations and new practices
3. Partner with research institutions and others to undertake research, support learning, and drive improvement
4. Increase internal capacity to support research and accelerate the adoption of evidence-based quality improvements
5. Share knowledge and innovative ideas externally through multiple channels



Caring and commitment

Whole-child and family- centred



Trust and respect

Accountability

Excellence



Innovation and continuous learning



Defining our purpose

Research:

An undertaking intended to extend knowledge through a disciplined inquiry and or systematic investigation.

Innovation:

Including inventions and diffusion of innovation. Novel devices processes conceived de novo or derived from a pre-existing model. The broad dissemination of new ideas procedures techniques materials and devices and the degree to which these are accepted and used.

Knowledge mobilization:

An umbrella term encompassing a wide range of activities relating to the production and use of research results including knowledge synthesis dissemination transfer exchange and co-creation or co-production by researchers and knowledge users.

The team



Taryn Eickmeier, Ph.D.

Executive Lead

Research, Innovation and Knowledge Mobilization



Maritza Basaran

Research Coordinator and Knowledge Broker



Janicka Auguste

Research Assistant and Speech-Language

Therapy Assistant

Student volunteers

Ariani Jagan

Karen Nimer

Abigayle Switzer

Sylvia Harnarain



Research & Innovation Committee

Our Research and Innovation Committee is a collaboration of internal experts, a Family Advocate and our Grandview Kids Research Associates. Together, our Committee identifies important topics to research and creative ways to inform practice.

- **Maritza Basaran**, Research Coordinator and Knowledge Broker (Chair)
- **Dr. Taryn Eickmeier**, Executive Lead of Research, Innovation and Knowledge Mobilization
- **Janicka Auguste**, Research Assistant and Speech-Language Therapy Assistant (Recorder)
- **Dr. Shannon Knights**, Developmental Pediatrician
- **Dr. Heather Shearer**, Family Advisory Committee Member
- **Dr. Meghann Lloyd**, Grandview Kids Senior Research Associate
- **Dr. Fiona Moola**, Grandview Kids Research Associate
- **Heather-Ann Burrel**, Registered Dietitian
- **Lindsay Gurr**, Physiotherapist
- **Nicole Jones**, Autism Therapy Assistant
- **Vareesha Khan**, Speech-Language Therapy Assistant



2022-23 in review

11

studies supported
through as a
recruitment partner

7

Lunch and learns
for Team
Grandview

400

attendees across
capacity building
lunch and learns

\$205,000

In external funding to support research in partnership with
Ontario Tech University.



Ontario Tech University and Grandview Kids reaffirm partnership
to advance research, innovation and education in Durham Region

Research

After a careful review, the Research and Innovation Committee approved the following studies in the 2022-23 fiscal year.

Childhood Cerebral Palsy Integrated Neuroscience Discovery System (Phase 3): CP-NET

Institution/Organization: CP-NET is an Integrated Discovery Program carried out in partnership with the Ontario Brain Institute

Primary Investigator(s): Darcy Fehlings

Role: Co-Investigators (Shannon Knights and Carolyn Hunt)

Funder: Ontario Brain Institute and partners

Study focus: CP-NET is working to improve understanding of cerebral palsy (CP) and accelerate the development of new treatments. It is exploring risk factors including genetic information, developmental and psychosocial outcomes, neuro-imaging findings and technology innovation for individuals with CP.

Measure of Process of Care 2.0 – Towards the new gold standard in measuring family-centred service

Institution/Organization: McMaster University

Primary Investigator(s): Peter Rosenbaum

Role: Recruitment partner

Funder: Canadian Institutes of Health Research (CIHR)

Study focus: This study explores what today's parents and caregivers need and want from healthcare services. Based on the parent feedback, an up-to-date tool that will reflect, and measure, parents' and caregivers' experiences of the delivery of health care services will be developed.

Understanding Health Care Experiences of Racialized Youth with Disabilities, their Caregivers, and the Health Providers who Serve Them – Services, Access, Navigation, and Interpretation (SANI)

Institution/Organization: Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital and Toronto Metropolitan University

Primary Investigator(s): Tim Ross and Fiona Moola

Role: Recruitment partner

Funder: Holland Bloorview Centre for Leadership Grant

Study focus: Explores the issues and challenges that racialized youth with disabilities and their parents experience while accessing and receiving paediatric health care services

Evaluation of a tool on workplace disability disclosure discussions (Youth toolkit study: Evaluation of a toolkit on workplace disability disclosure discussions for youth)

Institution/Organization: Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

Primary Investigator(s): Sally Lindsay and Sharmigaa Ragunathan

Role: Recruitment partner

Funder: Social Sciences and Humanities Research Council of Canada (SSHRC) – Canadian Institutes of Health Research (CIHR) Partnership Grant

Study focus: This study is evaluating how an online interactive PDF focusing on disability disclosure and workplace accommodations can enhance self-determination and workplace inclusion for youth with disabilities.

Evaluation of Virtual Care Services Offered to Children Across Ontario

Institution/Organization: McMaster University

Primary Investigator(s): Stelios Georgiades and Elyse Rosa

Role: Collaborator (Carolyn Hunt)

Funder: Empowered Kids Ontario Fund

Study focus: Evaluating the virtual care and foundational services offered by organizations across Ontario and how the delivery and outcomes of virtual care provided by organizations across the province can inform the future provision of services for children and their families.

Assessing validity and reliability of the Gross Motor Function Family Report (GMF-FR) for children and adolescents with cerebral palsy

Institution/Organization: McMaster University

Primary Investigator(s): Peter Rosenbaum and Paula Chagas

Role: Recruitment partner

Funder: N/A

Study focus: Exploring the Gross Motor Function Family Report tool to assess if it can be used to measure gross motor function at home and in the community.

Discrimination, ableism and racism hurt but inclusion can heal: Listening to the intersectional lived experiences of youth with disabilities and co-creating solutions [Youth Interview]

Institution/Organization: Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

Primary Investigator(s): Sally Lindsay and Sharmigaa Ragunathan

Role: Recruitment partner

Funder: Social Sciences and Humanities Research Council (SSHRC) and Holland Bloorview Kimel Family Opportunities Fund

Study focus: Exploring the diverse lived experiences of youth with disabilities and the intersection of disability with race, ethnicity and gender; and the causes and persistence of systemic discrimination, racism and ableism experienced by youth with disabilities.

Innovative language assessment for children with low motor and speech function: Engaging end users to understand the necessary conditions for implementing the C-BiLLT in Canada

Institution/Organization: Western University

Primary Investigator(s): BJ Cunningham

Role: Recruitment partner

Funder: Canadian Institutes of Health Research (CIHR)

Study focus: Exploring the necessary conditions for bringing a novel measure of language comprehension for children with cerebral Palsy and complex communication needs to Canada.

'Connecting for Care' - Using Social Network Analysis to Understand Knowledge Translation in Child Development and Rehabilitation

Institution/Organization: University of Manitoba

Primary Investigator(s): Kristy Wittmeier and Jeremy Layco

Role: Recruitment partner

Funder: Canadian Institutes of Health Research (CIHR)

Study focus: Investigating how groups of people involved in child development and rehabilitation connect with others to share and use knowledge. The overall goal of this work is to improve families' access to safe, effective health care and knowledge.

Air transportation experiences of caregivers of children and youth with physical disabilities: A survey study

Institution/Organization: Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

Primary Investigator(s): Tim Ross and Antonia Bellefleur

Role: Recruitment partner

Funder: N/A

Study focus: Explores the experiences of caregivers when navigating air transportation with their child(ren) or youth with a physical disability. Study findings will help to identify accessibility issues in air travel, as well as lines of inquiry for future research concerning accessible air travel.

Virtual hand-arm assessments for children with Cerebral Palsy: helping us to achieve equity in rehabilitation care and research

Institution/Organization: Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

Primary Investigator(s): Elaine Biddiss and Virginia Wright

Role: Co-investigators (Shannon Knights and Carolyn Hunt)

Funder: Canadian Institutes of Health Research (CIHR)

Study focus: This study supports the evidenced-based practice of virtual care for children with cerebral palsy (CP) through the development of valid and reliable methods of conducting virtual hand-arm assessments

Motor Skill Intervention for Children with Autism Spectrum Disorder: A 5-year follow up study

Institution/Organization: Ontario Tech University

Primary Investigator(s): Meghann Lloyd

Role: Recruitment partner

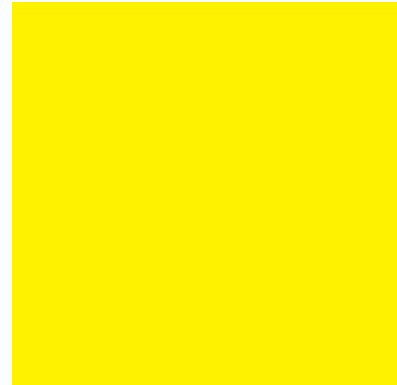
Funder: Social Sciences and Humanities Research Council of Canada (SSHRC)

Study focus: A 5-year follow-up study on a cohort of children with ASD who participated in an SSHRC-funded fundamental motor skill intervention between 2017 and 2020.



The screenshot shows the GrandviewKids website. The header includes the logo, navigation links (About Us, Calendar, Research, Contact Us, Careers), and buttons for Register and Donate. A language dropdown is set to English, and social media icons for Instagram, Twitter, and Facebook are present. The main navigation bar lists Services & Programs, Specialized Clinics, School & Community, Resources, Purchased Services, and I Want To... with a search icon. The breadcrumb trail reads: You are here: [Home](#) / [Research](#) / Clinical/Research Study Opportunities. The main heading is "Clinical/Research Study Opportunities" in large blue text. Below this, an "Overview" section explains that a list of actively recruiting studies is provided, divided into a drop-down bar. A list of eight study opportunities is shown, each with a right-pointing triangle icon:

- ▶ Measure of Processes of Care (MPOC) 2.0 – Towards the new gold standard in measuring family-centred service: Field-testing the new MPOC 2.0
- ▶ Caregiver-Mediated Early Years Programs: Focus groups
- ▶ Become a Family Advocate to help inform Inclusion, Diversity, Equity and Accessibility (IDEA) research
- ▶ Computer-Based instrument for Low Motor Language Testing, Parent and Caregiver Focus Group
- ▶ Discrimination, ableism and racism hurt, but inclusion can heal: Listening to the intersectional lived experiences of youth with disabilities and co-creating solutions [Youth Interview]
- ▶ Illustrating Inequities: The SANI Project
- ▶ Childhood Cerebral Palsy Integrated Neuroscience Discovery Network (CP-NET) – Research Database
- ▶ Province of Ontario Neurodevelopment Disorders-Network (POND-Network)



Innovation

In September 2022, Grandview Kids was a partner in delivering Access IO at the Abilities Centre.

This one-of-a-kind event brought together start-ups and Angel Investors alongside subject matter experts to discover emerging technology. These technologies all had the intended purpose of improving accessibility and inclusion for people of all abilities.

Catch a glimpse of this high-energy, high-impact event in this video by hosts Kleur Vision. [Watch the video here.](#)





Innovation

Liberi Exergames

In January, the Interprofessional Practice Team (IPT) participated in a focus group with the creators of Liberi-Exergames. As part of a therapeutic intervention, Liberi Exergames builds fitness while fostering a connection with other players. The target users are children and youth with cerebral palsy, however, Liberi Exergames allows for youth with different levels of physical abilities play together.

Hummingbird

In February 2023, Grandview Kids Speech and Language clinical staff were introduced to the Hummingbird, a wearable technology that detects vocal cord vibrations and converts them into switch outputs that can ‘talk’ to different interfaces such as computers, communication devices and more, empowering kids and adults alike to express their ideas. For children and their families in Durham Region, it opens newfound options and opportunities for learning and participation in their daily lives.

Brain-Computer Interface (BCI)

In March 2023, members from Holland Bloorview Kids Rehabilitation Hospital’s Clinical Brain Computer Interface (BCI) Program offered a demo and training session on the technology to members of Campbell’s Children’s School and Grandview Kids clinical staff. BCI translates brain activity into commands that can control technology that increases inclusion and participation for children and youth with disabilities. Together with BCI technology, children and youth can practice their BCI skills, create an art masterpiece, race remote control cars, play games and have fun.

Knowledge mobilization

A core function of the Research and Innovation Team is to bring the latest research evidence to Grandview Kids. This year, we engaged in the following knowledge mobilization activities to build internal knowledge.

Anxiety in Autistic Children: Assessment and Management

Dr. Brianne Baribeau



Dr. Baribeau is a child and adolescent psychiatrist who specializes in autism, neurodevelopmental disorders, psychopharmacology and neurogenetic syndromes. She completed her PhD in Clinical Epidemiology in 2022, focused on understanding longitudinal trajectories of anxiety in autism. In July of 2022, she will begin her position as a clinician scientist at Holland Bloorview Kids Rehabilitation Hospital.

She intends to focus her research program on translating novel discoveries in genomics into precision mental health treatment strategies for kids with neurodevelopmental disorders

Anxiety in autistic kids: Assessment and Management

Attendees learned how to:

1. Differentiate anxiety symptoms from other traits and behaviours associated with autism
2. Describe risk factors and longitudinal trajectories for anxiety in autistic kids
3. List first and second-line treatments for anxiety disorders in autism

ASD FEED-ed: An education platform designed for the purpose of educating children, youth, parents, caregivers and healthcare professionals about feeding in autistic children.

Dr. Sharon Smile, Rebecca Perlin, and Christie Raffaele



Dr. Sharon Smile
MBBS., DM(Paeds), Msc.



Rebecca Perlin
M.Cl.Sc. SLP(C) reg. CASLPO



Christie Raffaele
MSc(OT), PT Reg. (Ont.)



Attendees learned how to:

1. Empower clients and families with information to help start the conversation and build awareness about feeding and eating challenges in autism spectrum disorder, leading to earlier identification and management
2. Provide information about typical feeding milestones, common feeding challenges and evidence based treatment approaches through an ethno-culturally sensitive and multidisciplinary lens

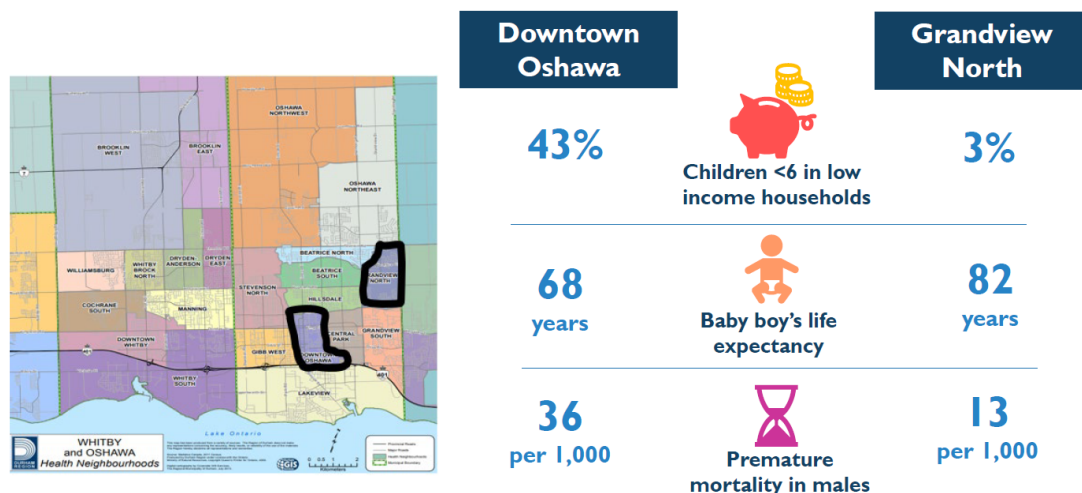
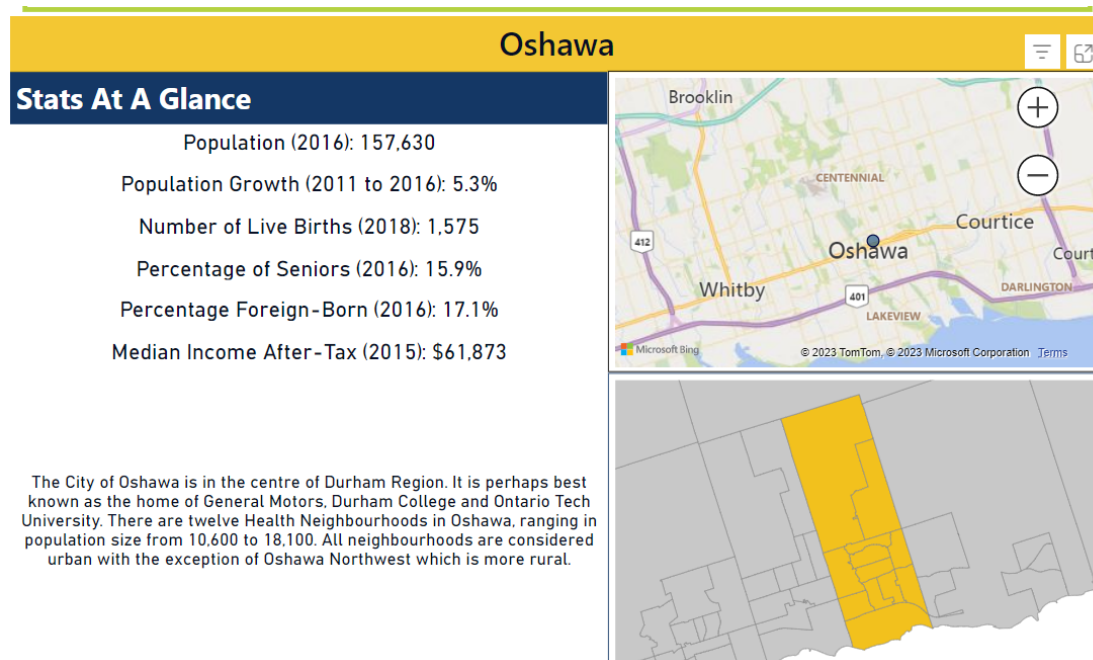
Durham Health Neighbourhoods

Alex Swirski and Busola Ayodele

Epidemiologists, Durham Health Department

Attendees learned about:

1. Health Neighbourhood boundaries and how they were created.
2. Priority Neighbourhoods and how they were determined
3. Indicators relevant to Grandview's work and indicator data sources
4. Online tools available for accessing Health Neighbourhoods data.



Presented to Grandview Kids on August 25, 2022

Lunch and learns with Grandview Kids Senior Research Associate - Dr. Meghann Lloyd



As Grandview Kids' Senior Research Associate, Dr. Lloyd has worked closely with us for over 10 years in furthering childhood disability research. We look forward to hearing about Meghann's recent research studies and what we can look forward to in the future.

Motor Behaviour and Children with ASD

Attendees learned about:

1. the importance of fundamental motor skills for children with ASD
2. how motor skills are related to other areas of development
3. how to implement simple strategies to work on motor skills at home

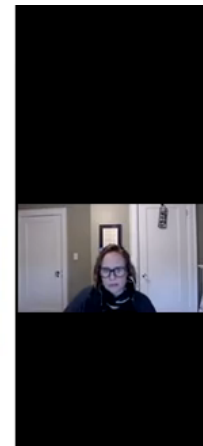
MOTOR SKILLS AND ASD

Fundamental motor skills and physical activity are frequently neglected in child development "*Cinderella*" (Rosenbaum, 2005)

Motor skills of young children with ASD are **not often a priority** (Gregor et al, 2018)

- Primarily focus on communication, social, and behavioural concerns

As children with ASD become adolescents their parents are recognizing a **significant gap** in their motor development and



Using administrative health database to study the health of Special Olympics participants

Attendees learned about:

1. Evidence that demonstrates the important health promotion effect that results from participation in Special Olympics
2. Why health care providers should consider promoting physical activity participation to individuals with intellectual developmental disorders.

Capacity-building coffee chats

Dr. Taryn Eickmeier

How to recognize BAD science: In-depth review of critical appraisal

Attendees learned how to:

1. Define the term critical appraisal
2. Identify critical components that establish good versus bad science
3. Critique research using validated critical appraisal checklists

How to - Write a Scientific Abstract

Attendees learned about:

1. The components of a scientific abstract
2. How to prepare an abstract for a research conference

Grandview Kids and Ontario Shores shared information about a new partnership and the Joint Research Ethics Board (JREB)

Attendees learned about:

1. The role of the JREB and expectations of members
2. How to express interest in joining the JREB

Tips and tricks from the Cochrane #BetterPoster movement

Attendees learned:

1. The process of developing, reviewing and presenting a poster presentation at a scientific conference.
2. What tools and resources are available to staff when developing a poster presentation

Grandview Kids

Evidence-informed practice

Evidence-informed practice can be defined as the combination of ***“the best available research with the experience and judgement of practitioners, children, youth and families to deliver measurable benefits.”***

Evidence-informed approach

- Practice practitioner knowledge and skills
- Research current best available research and evaluation
- People children, families and other users

Every child and youth living life at their full potential

Journal clubs

April 7, 2022, Dr. Shannon Knights led attendees through a discussion on a systematic review of effective (and ineffective) interventions in children with cerebral palsy.

Novak, I., Morgan, C., Fahey, M. C., Finch-Edmondson, M., Galea, C., Hines, A., Langdon, K., Namara, M. M., Paton, M. C. B., Popat, H., Shore, B. J., Khamis, A., Stanton, E., Finemore, O. P., Tricks, A., Velde, A. T., Dark, L., Morton, N., & Badawi, N. (2020). State of the Evidence Traffic Lights 2019: Systematic Review of Interventions for Preventing and Treating Children with Cerebral Palsy. *Current Neurology and Neuroscience Reports*, 20(2). <https://doi.org/10.1007/s11910-020-1022-z>

March 2023 Grandview Kids' Registered Dietitians, Heather-Ann Burrell and Shelley Williams reviewed a systematic review on dietary interventions for autism spectrum disorder.

Amadi, C. N., Orish, C. N., Frazzoli, C., & Orisakwe, O. E. (2022). Dietary interventions for autism spectrum disorder: An updated systematic review of human studies. *Psychiatriki*. <https://doi.org/10.22365/jpsych.2022.073>

Type of Study

- Systematic Review
 - Identify, appraise and synthesize all empirical evidence that meets eligibility criteria to answer a research question
 - Uses explicit methods aimed a minimizing bias to produce reliable findings

(Cochrane, n.d)

A

Figure 1. Traditional Hierarchy of Evidence (Murad et al, 2016)

Heather-Ann Burrell

Shelley Williams

Shannon Knights

Tara Colquhoun

Malissa Masson

Marcia Newell

Orientation e-Modules

To ensure every member of Team Grandview has the same working knowledge of research, innovation and knowledge mobilization, this year we partnered with Trent University and had 30 post-graduate students design three interactive e-modules for our staff.

What is Research: This module defines research, explains how research can be empowering to staff, clients and their families and reviews how staff can engage with research at Grandview Kids.

What is Innovation: This interactive module defines innovation, provides examples of innovation in the children's health and rehabilitation sector and describes innovation projects at Grandview Kids.

What is Knowledge Mobilization: This training module reviews the definition of knowledge mobilization and describes knowledge tools and knowledge mobilization activities in research settings.

As we evaluate the outcomes and impact of the e-modules, we will refine and update to meet the needs of Team Grandview.



Presentations

Wintle, R., Fehlings, D. L., Zarrei, M., Engchuan, W., Thiruvahindrapuram, B., Higginbotham, E.J., Thapa, R., Behlim, Wei, J., Danthi, P.S., Pellecchia, G., Nalpathamkalam, T., S. Gharari, R., Patel, R., Shaath, R., Trost, B., **Knights, S.**, Samdup, D., McCormick, A., **Hunt, C.**, Kirton, A., Kawamura, A., Mesterman, R., Gorter, J.W., Dlamini, N., Merico, D., Yuen, R.K.C., Shevell, M., Stavropoulos, D.J., Oskoui, M., and Scherer, S.W. (2023).

Comprehensive Whole-Genome Sequence Annotation to Elucidate the Genetic Architecture of Cerebral Palsy. American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), 77th Annual Meeting, Abstract.

Smith, E. (2022). Employment Equity. Disability and Work in Canada (DWC) Conference, Virtual

Wintle, R., Fehlings, D. L., Zarrei, M., Engchuan, W., Thiruvahindrapuram, B., Higginbotham, E.J., Thapa, R., Behlim, Wei, J., Danthi, P.S., Pellecchia, G., Nalpathamkalam, T., S. Gharari, R., Patel, R., Shaath, R., Trost, B., **Knights, S.**, Samdup, D., McCormick, A., **Hunt, C.**, Kirton, A., Kawamura, A., Mesterman, R., Gorter, J.W., Dlamini, N., Merico, D., Yuen, R.K.C., Shevell, M., Stavropoulos, D.J., Oskoui, M., and Scherer, S.W. (2022). Using whole genome sequencing to understand the genetic architecture of cerebral palsy in a Canadian cohort. American Society of Human Genetics (ASHG), Annual Meeting, Abstract.



Funding

2023-2026

Building knowledge and understanding of the intersection of race and disability in accessing paediatric rehabilitation services

Investigators: Ontario Tech University, Grandview Kids, The Regional Municipality of Durham

Funding Name: Social Sciences and Humanities Research Council of Canada

Funding Role: Co-Principal Investigator

Funding Start Date: June 2023

Total Funding: \$200,000

2023-2024

Trends in access to government-funded rehabilitation services between 2016-2022 for families of children and youth with disabilities living in the Durham Region: a pilot study

Investigators: Ontario Tech University and Grandview Kids

Funding Role: Collaborator

Funding Start Date: June 2023

Total Funding: \$5,000



Partnerships

In February 2023, long-established community partners Grandview Kids and Ontario Tech University are celebrating their shared commitment to advancing research, innovation and education in Durham Region through a formal Memorandum of Understanding (MOU). The MOU will enable further exploration of experiential learning opportunities for both undergraduate and graduate students, joint research activities across different faculties, academic and non-academic programming, innovation, and entrepreneurship that connects students and faculty with the community, and builds new engagement and outreach across Durham Region and beyond.

The agreement builds on Ontario Tech Faculty of Health Sciences Associate Professor Dr. Meghann Lloyd's decade-long leadership as the Grandview Kids Research Associate, conducting research and championing advocacy for children with disabilities and their families. As part of solidifying the MOU, Dr. Lloyd will continue in her role as Grandview Kids' Senior Research Associate, and Dr. Taryn Eickmeier, Executive Lead for Research Innovation and Knowledge Mobilization at Grandview Kids, has been warmly welcomed by Ontario Tech as an Adjunct Professor.



