

Developing a Resource to Support Application of the Canadian 24-Hour Movement Guidelines for the Early Years in Occupational Therapy

Letter of Information for Parents

Principal Investigator:

Dr. Trish Tucker, PhD, Faculty of Health Sciences, University of Western Ontario Phone: (519) 661-2111 ext 88977 Email: ttucker2@uwo.ca

Funding:

This project is being funded by the Canadian Institutes Health Research, Doctoral Research Award.

Invitation to participate:

You are being invited to participate in a student research project which seeks to create a practice resource for Occupational Therapists to implement the Canadian 24-Hour Movement Guidelines for the Early Years with preschoolaged clients (aged 3-4 years) with developmental disabilities, because you are a parent of a child under the age of 8 with a developmental disability who accessed occupational therapy services during the child's preschool years (ages 3-4).

Purpose of this letter:

The purpose of this letter is to provide you with the information needed to make an informed decision regarding your participation in this study.

Why is this study being done?

This research aims to create a tailored practice resource for occupational therapists to implement the Canadian 24-Hour Movement Guidelines for the Early Years with preschool-aged clients (aged 3-4 years) with developmental disabilities. These guidelines recommend a balanced approach to physical activity, sedentary time, and sleep, which is crucial for the healthy development of all young children. However, occupational therapists, who play a key role in supporting children with developmental disabilities, have not been using these guidelines in their practice and have requested supports to do so. This study will use a co-design approach to develop a guideline implementation resource for occupational therapists.

Inclusion and exclusion criteria:

You are eligible to participate in this study if you:

- (1) self-identify as a parent of a child under the age of 8 years with a developmental disability;
- (2) self-identify as having experience using occupational therapy for your child, during their preschool years;
- (3) are able to speak, read, and write in English; and,
- (4) have access to the internet.

Individuals will be excluded from this study if they:

(1) do not self-identify as a parent of a child under the age of 8 years with a developmental disability;

(2) do not self-identify as having experience using occupational therapy for their child, during their preschool years;

- (3) are unable to speak, read, and write in English; and/or,
- (4) do not have access to the internet.

What are the study procedures?

We are asking four parents with lived experience of parenting a child with a developmental disability who accessed occupational therapy services during their child's preschool years to participate on an advisory group in a co-design study to co-lead the development, design, and evaluation of a new guideline implementation resource for occupational therapy practice. The advisory group will also include six occupational therapists with experience working with preschoolers with developmental disabilities, and four researchers from Western University. Six topic area experts from Canadian universities will also act as consultants to the advisory committee to ensure the developed resource is scientifically appropriate.

Over the course of the study, the advisory group will participate in four virtual 1-hour workshops on Microsoft Teams to create this resource. These will be conversation-based and collaborative. In workshop 1 the advisory group will meet for introductions and establish consensus on format and requirements for a resource to incorporate the guidelines into practice. The expert consultants will then meet separately to provide input on a prototype of the resource. Workshop 2 for the advisory group will involve a think aloud session. Think-aloud involves participants verbalizing their thoughts while working through the prototype. We will work through the prototype together, making adjustments as required. Occupational therapists then be asked to test the prototype of the resource with their clients in practice. We will collectively decide on timelines needed for testing the prototype with clients in practice. Workshop 3 will subsequently involve debriefing the use of the prototype in practice with the whole advisory group. Workshop 4 will involve generating live consensus to resolve remaining issues, with involvement of all partners (advisory group and consultants) to finalize the resource.

Workshops will be recorded and transcribed verbatim to ensure what is discussed is accurately recalled. To ensure qualitative rigor, we will not allow participants to opt-out of recording, so if you do not wish to be recorded please do not consent to partake in the study. Anonymized unattributed direct quotes may be used in academic publications. All communication and scheduling for this study will be completed via email, to your preferred address.

Do I have to participate in this study?

Your participation in this study is completely voluntary. You do not have to participate and can refuse to comment in workshops.

What are the risks and harms of participating in this study?

There are no known or anticipated risks or discomforts associated with participating in this study. There are no costs to you for participating in the study. As personal identifiers will be collected, there is always the risk of a privacy breach. Please see "How will participants' information be kept confidential?" below to learn more about the steps that will be put in place to protect your data. Teleconferencing/videoconferencing technology has some privacy and security risks. It is possible that information could be intercepted by unauthorized people (hacked) or otherwise shared by accident. This risk cannot be completely eliminated. We want to make you aware of this. You do not waive any legal rights by consenting to this study.

What are the benefits?

By participating in this research, the possible benefits to you may be the potential to advance your knowledge in physical activity, sedentary behaviour, and sleep time in early childhood, having a voice in the development of the resource, and developing new connections across the country. By developing the first 24-Hour Movement Guideline resource for occupational therapists, the possible benefits to society may include that children with developmental disabilities could receive the numerous health benefits of engaging in the movement behaviour recommendations of the guidelines. Participants may also experience no benefit from participation in this study.

Can participants choose to leave the study?

Participation in the study is voluntary. Participants may choose to leave the study at any time, and will not be required to participate in further workshop sessions with no effect to them, by emailing the Principal Investigator Dr. Trish Tucker via email (<u>ttucker2@uwo.ca</u>) and indicating their wishes. When analyzing workshop transcripts, the focus is on the group conversation rather than what any single person said. This means the insights come from how everyone interacts. If a part of the conversation is removed, it can be hard to understand the rest of the discussion and might affect how it can be analyzed. Taking out data from one person can also impact the overall insights from the group and limit what others can contribute. For this reason, participants can choose to withdrawal the consent to use their quotations but will not be able to remove their data from workshop records and data analysis.

How will participants' information be kept confidential?

We will keep your data confidential and secure. Only the research team and representatives of the Western University and its Health Sciences Research Ethics Board that oversees the ethical conduct of this study will have access to these data.

The workshops will be collected via Microsoft Teams (privacy policy), and transcribed via NVivo (privacy policy). Both resources use encryption technology and restricted access authorizations to protect all data collected. Western's Microsoft Teams and NVivo servers are in the United States, and privacy standards are maintained under the EU-U.S. and Swiss-U.S. Privacy Shield frameworks. The data will then be exported and securely stored on Western University's server. Your name will not be associated with the collected workshop data. The results of this study will never individually identify you. Any direct quotes used from workshops will only be presented in anonymized format with identifying information removed.

All data obtained will be stored in secured computer files on Western University's, password encrypted computer server. All data will be retained for 7 years after the results of the study have been published. After this period, all data will be destroyed (i.e., the computer data will be erased). Your name and email will be stored securely and will only be used to contact you for matters pertaining to your voluntary participation in this study, and to provide you with your compensation.

Are participants compensated to be in this study?

As a thank you for participating in this study, and in line with the School of Occupational Therapy's compensation rate for practitioners facilitating programming for students, advisory group members (i.e., parents and occupational therapists) will be compensated at a rate of \$50 per one-hour workshop, for their participation in this study. Participants will be compensated in the form of an <u>Everything Card</u>.

What are the Rights of Participants?

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. You do not waive any legal right by consenting to this study.

Publication of the results:

When the results of the study are published, your name will not be used. You may elect to include your name in the acknowledgements section, to recognize your contributions. If you would like to be named in the acknowledgements section, or if you would like to receive a copy of the overall results of the study, please contact Leah Taylor by email: ltaylo83@uwo.ca.

For further information on this study, you can contact the Principal Investigator,

Dr. Trish Tucker at (519) 661-2111 ext 88977 or ttucker2@uwo.ca.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, 1-844-720-9816, email: <u>ethics@uwo.ca</u>. The REB is a group of people who oversee the ethical conduct of research studies. The HSREB is not part of the study team. Everything that you discuss will be kept confidential.

You can print this page to keep this letter for future reference. A copy of your signed consent form will also be signed by the research team, and emailed to you in PDF format, for your records.

Consent

Each participant will receive a unique link to a password protected Letter of Information and Consent in Qualtrics, a secure, online platform. The password will be sent to you directly via secure email, and will be unique to each participant to verify your identity.