

What if I have more questions?

You may call the Local Study Contact in your area:

Or the Main Study Contact:

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What is *CanChild*?

This study is being coordinated through *CanChild* Centre for Childhood Disability Research. *CanChild* is a team of researchers and service providers who meet at McMaster University, in Hamilton, Ontario, Canada. *CanChild's* mission is to improve the life quality of children and youth with disabilities and their families.

If you would like to know more about *CanChild* and the other types of research we are doing, please visit our website: www.canchild.ca

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ON
TRACK

Monitoring
Development
of Children
with Cerebral Palsy
or Gross Motor Delay

An Invitation For
Families
To Participate



What is this study about?

We need to better understand how young children who have difficulties with movement activities progress and develop in their -

- Balance abilities
- Fitness
- Strength
- Health
- Range of motion
- Self-care
- Everyday play and activity participation

We plan to monitor how children with motor and movement delays progress to help develop future programs and services that support individual children based on their unique features.

Why are we doing this study?

The childhood years are an important time for children to learn and develop skills to the best of their abilities. This study will provide important information that will help support young children who have motor delays and problems with muscle tone and balance. The assistance families and health care professionals can give during these developmental years will have benefits that are long lasting.

How will this study be useful?

This study will determine how young children with cerebral palsy or gross motor delays progress in many aspects of their physical development and participation in daily life. The information collected from this study will help therapists and parents **monitor if a child is developing as expected** in his or her physical development and participation. Then, the health care professionals working with children can use the results of this study, in combination with our previously completed Move & PLAY study results, to provide **the services that are most beneficial and meaningful for each child** and their family members. We plan to **report this new and useful information to therapists and parents across North America.**

Who are the children and families we are inviting to participate?

Your family is eligible to participate in the study if:

1. You have a child between 18-months and 11-years of age
2. Your child has a
 - a. diagnosis of Cerebral Palsy, **OR**
 - b. delayed motor development, muscle stiffness, and difficulties with balance and moving.

Families from many regions of Canada and the USA are being asked to participate. Your therapist can tell you if you are eligible for the study.

What are we asking you to do?

You and your child will be asked to participate on **5 occasions, over a two-year period.**

First visit (if you agree to participate):

Your Child: A therapist will assess your child's balance, strength, range of motion, and distance walked in 6-minutes (if your child is able to walk and is over 3-years of age) at your home or during a clinic visit. Some of these assessments will be familiar to you and may be a part of your usual visits. This will be completed within one hour.

You: We will give you a package of questionnaires asking you questions about your child and your family, and the services you receive (as well as your child's fitness, health, self-care abilities and participation in life activities). They will take approximately one hour to complete and can be completed at your own convenience before or during your child's visit with the therapist.

Second, third, fourth, and fifth visit – every 6-months after the first visit:

Your Child: A therapist will assess your child's balance, strength, range of motion, and walking distance using the same tests done at the first visit.. This will take less than one hour and will be done at your home or during a clinic visit.

You: You will fill out the same questionnaires about your child that you completed in the first visit and can be completed before or during your child's visit with the therapist. This will be completed within one hour.

Will my child benefit from this study?

There is not an *immediate* benefit to your child or your family for participating in this research study; however, we will provide you with your child's individual test scores that you may wish to discuss with your care providers. Your assistance and participation are very valuable! With the help of a large group of families like yours, we will learn how to monitor and provide future services for children with CP or gross motor delays.

