



“We are happy to participate in this study in hopes that my son's experience and challenges and the results of your findings will indeed help someone else with unique challenges and abilities...Thank you so much to all of the great therapists out there!” *parent participating in the study*

On Track Study Report to Families

March 2018

What is On Track?

The *On Track Study* (2012-2017) involved 708 children with cerebral palsy and their families, researchers, and therapists from across Canada and the United States.

Health care providers define cerebral palsy (CP) as a group of disorders of the development of movement and posture. People with CP often have related sensation, perception, cognition, communication, and behavior concerns as well as epilepsy and developing muscle and bone problems.

The *On Track Study* set out to better understand how young children (ages 2-12 years) with CP who have difficulties with movement activities progress and develop in these areas:

- Balance
- Strength
- Range of Motion
- Endurance
- Impact of Health Conditions on Daily Life
- Participation in Family and Recreational Activities
- Performance in Self-care Activities

What we learn from studying a large number of children with motor and movement delays can help develop future programs and services that support individual children

based on their unique features. On Track Study results can help health care providers and families with questions like these...

How should I expect my child to develop?

How can health care providers and the health care system help us make the best decisions about my child's health and rehabilitation care?

By understanding what helps children progress in their abilities and by monitoring progress, we can focus on a collaborative approach to providing individualized services that are most beneficial.

Researchers created longitudinal graphs and reference percentiles based on children's assessments over a 12-month timeframe, similar to the growth charts used by pediatricians.

The longitudinal graphs help with considering future development based on children's functional ability. The percentile results are a tool that therapists can use in collaborative

discussions with a family to look at whether a child with CP is progressing as expected, more than expected, or less than expected, depending on his/her functional ability level in relation to other children with CP.

Therapists can use the materials created through the *On Track Study* to:

- RECORD your child's current assessment scores and how your child is progressing, relative to what we might expect.
- DISCUSS your child's strengths and important areas for improvement and make notes to help individualize your child's treatment plan.

Why is it important to monitor progress over time?

For families who find it helpful, this type of developmental monitoring is a place to start the conversation about what we might expect to see based on assessments of children with CP in similar functional levels.

The childhood years are an important time for children to learn and develop skills to the best of their abilities. *On Track Study* results give health care providers important information that will help support young children with CP who have motor delays and problems with muscle tone and balance. The assistance families and health care professionals can give during these early years will have benefits that are long lasting.

Summing it all up!

The graphs and tables created in the *On Track Study* will illustrate how young children with CP progress in many aspects of their physical development and participation in daily life. This information 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.

The *On Track Study* is now ready to share the materials resulting from the study with therapists and parents across North America.

Important Take-away Messages

- ❖ We offer a system for monitoring progress in the context of what we might expect to see based on assessments of children in similar functional levels of CP.
- ❖ We provide a framework for making decisions about interventions and supports for young children (ages 2-12) with CP and their families.
- ❖ Our results encourage a broader focus of rehabilitation services, to include not only development of motor abilities, but also enhancing performance in self-care and participation in family and recreational activities.
- ❖ We value the important role of parents to provide therapists with information about many unique aspects of their child and family. Collaboration is the foundation for planning the best treatments for each individual child.

We thank the participating children and families, whose continued involvement made this study possible, the important contributions of the regional coordinators, and the 90 therapists across North America who assessed children during the study.

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