



# Developmental Trajectories of Impairments, Associated Health Conditions and Participation of Children with Cerebral Palsy: the 'On Track' Study

## Executive Summary Secondary Purpose

July 2018

### The purpose of this study

The On Track study results provide useful and important information to assist with answering two client-centered questions:

- 1) "How should I expect my child to develop?"
- 2) "How can clinicians and care delivery systems help me make the best decisions about my child's health and rehabilitation?"

The primary purpose of the On Track study was to determine how children with cerebral palsy (CP) progress in development of key body functions, performance in self-care and participation in family and recreation activities via creation of longitudinal trajectories and percentile graphs for physical development and participation. This information will help children, families and health care professionals understand children's prognosis, as well as strengths and limitations and track whether children are progressing 'as expected,' 'more than expected,' or 'less than expected.' These results are summarized in an Executive Summary, December 2017.

A **secondary purpose** was to explore the relationships of rehabilitation services received to the children's development as determined by the percentile graphs in balance, endurance, self-care activities and participation in family and recreational activities. This information will help children, families and health care professionals in their considerations for rehabilitation service provision.

### How this study was conducted

A prospective cohort research design was used to collect data from 708 children with CP, age 1.5 to 11.9 years at study onset. Children were recruited from 43 sites, clinics, and/or practices across Canada and the United States. Each child enrolled in the study was followed over a period of at least one year and maximally two years (every 6 months), with two to five data collection points per child and family. Children were assessed on standardized measures of body functions, health conditions, and activity, which were shown through previous study to be significant determinants of gross motor abilities,<sup>1</sup> self-care performance,<sup>2</sup> and participation in recreation and leisure.<sup>3</sup> Trained physical and occupational therapists measured balance, range of motion, strength and endurance using valid and reliable tests. Parents completed questionnaires about their family demographics and about their children's endurance, health, performance of self-care activities and participation in family and recreation activities. Therapists and parents collaborated to classify children within five functional levels for gross motor, manual, and communication functions. Body function and participation data from all visits were analyzed by linear and nonlinear mixed-effects modeling to create longitudinal trajectories by children's functional motor ability levels as measured by Gross Motor Function Classification System (GMFCS).<sup>4</sup> Data from baseline, 12-month, and 24-month visits were analyzed via quantile regression to construct cross-sectional reference percentile graphs for each measure by GMFCS levels.<sup>4</sup>

Parents also completed questionnaires that detailed the rehabilitation and health services their children received including estimates of the amount, focus and family centeredness of services. Using separate multinomial models, physical, occupational and speech/language therapy service amount, focus, and family centeredness, controlling for country, were explored to understand how services related to children's development of balance, endurance, self-care activities and participation in family and recreational activities.

### Key Findings

Rehabilitation therapists and families suggest that these are the key findings of the secondary purpose of the On Track study:

1. Decision-making regarding the most effective and efficient amount of therapy services, focus of therapy services, and manner in which therapy services are provided is complex, due to decisions not only relying on the effectiveness of intervention but also the availability of therapists and families, training of therapists, therapist and children's environments, and healthcare and insurance policies.<sup>5,6</sup>
2. Information on broad associations between aspects of therapy services and physical development and participation in daily life outcomes assists healthcare professionals in collaboration with families to provide services that are most beneficial and meaningful for children and their family members, which should increase the efficiency and effectiveness of services.
  - a. Relationships of services to outcomes based on categorical percentile groups of developing "as expected", "more than expected", and "less than expected" showed clinically meaningful positive relationships for:
    - i. A focus on health and well-being to participation outcomes, suggesting that health conditions should be routinely monitored with appropriate referrals made for issues that impact the children's daily life

- ii. A focus on structured play and recreation activities to participation outcomes, suggesting that therapists consider providing task specific practice within meaningful play and recreational activities
- iii. Use of family-centered care and the extent parents perceived their children's needs were being met by services to participation outcomes, suggesting that therapists should discuss and collaborate with families as service decisions are made and should value the families' thoughts and desires
- b. Amount of services was related to the children's functional ability level, their country, and their age but more sessions of therapy did not relate to more positive outcomes.
  - i. Children with higher functional ability and residents of Canada receive fewer sessions of therapy/year. Relationships of number of therapy sessions/year with age were more complex with differences in amount of services varying based on the children's GMFCS levels.
  - ii. Based on other research, changes in movement ability have been shown to relate to the amount of time individuals are able to practice the particular tasks.<sup>6</sup> We suggest that this does not have to relate directly to the number of sessions with a therapist and therapists should consider collaboration with families to maximise activity outside of the therapy session, but this premise needs to be specifically studied in future research.

### **How Administrators and Policy Makers Can Help:**

- Recognize the complexity of development associated with body structure/function and participation in life activities outcomes for young children with CP
- Recognize the complexity of service provision and the challenge service providers experience in developing and planning services for children with CP and their families
- Ensure that service providers have opportunities to be mentored appropriately to develop the necessary expertise especially in the provision of family-centered care to support children with CP and their families
- Ensure that service providers have reimbursable time to have collaborative discussions with children with CP and their families
- Provide services with both formal and informal supports for all children with CP across functional ability levels and ages
- Recognize the importance of indirect therapy time to access appropriate information and resources for children and families

The results of this study are being summarized in peer-reviewed manuscripts, summaries for families, videos and within interpretive tools illustrating how to best use and communicate the findings with families. Documents, as available, which were developed and refined by the research study team, including parent consultants, study assessors, and an independent group of parents of children with CP can be found on the On Track study website (<https://www.canchild.ca/en/research-in-practice/current-studies/on-track>).

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