



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

**Executive Summary**

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## **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 and performance in self-care and participation in family and recreation activities. The primary study aims were to create longitudinal trajectories and percentile graphs for physical development and participation. The goal is that these will:

- help children, families and health care professionals understand individual children's prognosis, as well as strengths and limitations, and
- track whether children are progressing 'as expected,' 'more than expected' or 'less than expected.'

The information from this study enables collaborative developmental monitoring to plan individualized services for children with CP.

## **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.

## **Key Findings**

Rehabilitation therapists, youth with CP, and families suggest that these are the key findings of the On Track study:

- The study results provide evidence-based data that describe how children with CP progress in many aspects of their physical development and in the outcome of participation in daily life from 1.5 to 12 years of age.
- Consistent use of the standardized measures to track the clinical course of children's physical development and participation will assist therapists and parents to proactively, comprehensively and collaboratively plan services around fundamental goals identified by families, to mitigate secondary impairment risk, and to optimize a child's health, function, and participation.<sup>5,6</sup>
- Creation of longitudinal trajectories for children with CP by GMFCS levels enables families and healthcare providers to discuss children's current development in comparison to others with similar functional ability in broad-brush strokes and

to anticipate changes that are likely to follow. Longitudinal trajectories therefore may assist with realistic goal-setting and increasing the efficiency of service provision.

- The percentile graphs indicate how a child is developing relative to peers of the same GMFCS level and of a similar age, permitting an understanding of a child's individual strengths and limitations at one point in time. Percentile graphs can also be used to evaluate individual children's change over time to identify children who are progressing 'as expected', 'more than expected' or 'less than expected'. Along with information from the longitudinal trajectories, understanding how individual children are progressing informs shared decision making relative to service planning and potentially increases the effectiveness of services.

### How Collaborative Developmental Monitoring Should be Administered by Front-Line Service Providers:

- Use the principles of family-centred care.
- Encourage and support families to be ready, willing and able to participate in decisions.
- Use knowledge of family preferences and priorities of both outcomes and collaborative developmental monitoring.
- Collaboratively decide: what measures to use, how frequently to administer them, how the child and family want to be involved in examination and monitoring, and how to document and share the information.
- Child, family and service providers **together** set goals, do an examination, evaluate the information, plan for intervention and do progress monitoring.
- Consider health promotion and prevention of secondary impairment.

### How Administrators and Policy Makers Can Help:

- Recognize the complexity of development associated with body function and participation in life activities outcomes for children with CP.
- Foster a culture that values the use of research-based evidence to understand the uniqueness of each child with CP as a step in optimizing each child's outcomes, a position that is consistent with a health equity approach to care.
- Support children and families when they advocate for comprehensive developmental monitoring.
- Recognize the challenge service providers experience in developing and planning services for children with CP and their families.
- Ensure that service providers have the time and opportunities to be mentored appropriately to develop the necessary skills and expertise to support children with CP and their families.
- Ensure that service providers have reimbursable time to do developmental monitoring and have collaborative discussions with children with CP and their families.
- Provide services with both formal and informal supports for all children with CP across GMFCS levels and ages.
- Recognize the importance of indirect therapy time to access appropriate information and resources for children and families.

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### References

1. Bartlett DJ, Chiarello LA, McCoy SW, et al. Determinants of gross motor function of young children with cerebral palsy: A prospective cohort study. *Developmental Medicine & Child Neurology*. 2014;56:275-82.
2. Bartlett DJ, Chiarello LA, McCoy SW, et al. Determinants of self-care participation of young children with cerebral palsy. *Developmental Neurorehabilitation*. 2014;17:403-13.
3. Chiarello L, Bartlett DJ, McCoy SW, et al. Determinants of participation in family and recreational activities of young children with cerebral palsy. *Disability and Rehabilitation*. 2016;38:2455-68.
4. Palisano R, Rosenbaum P, Bartlett D, Livingston M. Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine and Child Neurology*. 2008; 50: 744-750.
5. Chiarello LA, Palisano R, Bartlett DJ, McCoy SW. A multivariate model of determinants of changes in motor abilities and engagement in self-care and play of young children with cerebral palsy. *Physical and Occupational Therapy in Pediatrics* 2011;31:150-68.
6. Bartlett DJ, Chiarello L, McCoy SW, et al. The measurement model of the Move & PLAY study: The protocol of a study using comprehensive outcomes research in rehabilitation. *Phys Ther* 2010;90:1660-72.