Developmental Trajectories of Impairments, Health, and Participation of Children with Cerebral Palsy

Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay

On Track Study
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Summary / Overview

Cerebral palsy (CP) is the most prevalent childhood onset neuromuscular condition, and over 90% of all individuals with CP live well into adulthood. Beginning when their children are young, families need evidence to guide decisions on effective and cost efficient services and supports that build capacity and prepare children and youth for life as adults. The clinical manifestations of CP change with age, including a decline in motor function, which occurs in late childhood through adulthood, yet changes over time in postural control (a defining feature of CP), secondary impairments, and co-occurring health conditions have not been quantified. We propose to create developmental trajectories of impairments that change throughout childhood, the number and impact of associated health conditions, self-care abilities, and participation in family and community recreation. Creation of developmental curves would enable families of children with CP and health care providers to: 1) monitor a child’s development (developmental surveillance), 2) anticipate a child’s future strengths and needs (prognosis), and 3) proactively plan efficient services and supports to optimize a child’s health, function, education, social participation, and prevention of secondary impairments.
Objectives

1. To establish reference percentile curves for primary (balance) and secondary (range of motion, strength and endurance) impairments that change throughout childhood, as well as number and impact of associated health conditions, that are significant determinants of outcomes of acquisition of basic motor abilities, self-care, and participation in life activities for young children with cerebral palsy (CP) from the age of 18 months through elementary school-age in each of the five levels of the Gross Motor Function Classification System (GMFCS).

2. To explore a system of multivariate classifications incorporating the GMFCS, the Manual Ability Classification System (MACS) and the Communication Function Classification System (CFCS).

3. To establish reference percentile curves for components of the Child Engagement in Daily Life Measure (i.e. Self-Care and Participation in Leisure Activities) for children with CP from the age of 18 months through elementary school age for either combinations among the GMFCS, the MACS, and the CFCS, or for each of five levels separately for each system, pending preliminary analyses to met objective 2 (above).

4. To replicate a method for families and therapists to ascertain whether children within each of the levels of the various classification systems are developing ‘as expected,’ 'better than expected,' or 'more poorly than expected' on these determinants and outcomes.

5. Create and compare longitudinal developmental curves for impairments, physical activity, associated health conditions, and participation in self-care and recreational activities for children with CP grouped by 5 functional classifications.

6. Identify and compare the characteristics (intensity, focus, family centeredness) of services of children whose developmental trajectories for impairments and participation in self-care and recreation are predictive of the most optimal change (above 50th percentile).
Research Plan

We will use a prospective longitudinal observational cohort design. Eight hundred and seventy-five children with CP between the ages of 18 months and 10 years, stratified by Gross Motor Functional Classification System Level (GMFCS), will be recruited from several regions across Canada and the United States, using quota convenience sampling. Each child enrolled in the study will be assessed on standardized measures of body functions and structures, health conditions, activity, and participation a total of five times, once every 6 months (over a period of two years) or a total of two times (12 months apart). At each data collection point, we will collect data on general endurance, health conditions, and participation in self-care and recreation activities. All data collected over the 2-year interval will be used in the analysis. The LMS method of Cole and Green will be used to construct reference percentiles for all outcomes. The end product will comprise reference percentile curves plotted at the 3rd, 5th, 10th, 25th, 50th, 75th, 90th, 95th, and 97th percentiles. We also characterize 2-year change in percentiles as “better than expected,” “as expected,” or “poorer than expected” given the typical variability in the percentiles. To investigate the associations of health service characteristics with longitudinal trajectories, the health service variables will be added as predictors to the linear and nonlinear mixed-effects analyses.

Impact
Creation of longitudinal developmental curves for balance, muscle strength, joint range of motion, impact of health conditions associated with CP, physical activity, endurance for activity, and participation in self-care and recreation activities, and knowledge of characteristics of services received by children with CP with “better than expected” and “as expected” developmental trajectories will lead to improved efficiency in utilization of rehabilitation services. Knowledge of developmental trajectories in multiple areas will enable families and service providers to monitor change over time and apply this evidence when making decisions about current and future services. The longitudinal developmental curves will provide evidence for developmental surveillance and anticipatory guidance whereby families anticipate and plan for the future. The description of service provisions related to children with CP who are performing the best as they age will provide a gold-standard for optimal development.

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Participating Sites
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Related Link
CanChild Center for Childhood Disability Research

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