



## Movement and Participation in Life Activities of Young Children with Cerebral Palsy:

### Executive Summary

May 2012

#### The purpose of this study

The purpose of the Move & PLAY study was to gain a better understanding of the child, family, and service delivery factors that support the development of movement abilities and participation in self-care, recreation, and play of preschool children with cerebral palsy (CP). Participation in play is the primary activity of young children. Promoting children's participation in all aspects of daily life is an important goal of rehabilitation that helps children learn new things and contributes to self-efficacy. The preschool years are a critical period for these children; early success predicts a child's future participation in education, social roles, and employment. Rehabilitation therapists who work with these children and their families are challenged to select the best interventions because of the complexities of the multiple factors that contribute to development. We believe the results of the Move & PLAY study address these concerns by providing research-based evidence about the factors that contribute to a range of outcomes important to young children with CP and their families.

#### How this study was conducted

A prospective cohort research design was used to test a conceptual model of the multiple determinants of basic motor abilities and participation in self-care, recreation, and play of young children with CP. Four hundred and thirty children with CP between the ages of 18 months and 4.5 years were recruited from centres across Canada and the United States. Each child enrolled in the study was followed over a period of one year, with three data collection points. The results of this study were summarized in 12 dissemination pieces which were developed and refined by the research study team, including the dissemination facilitator, parent consultants, study assessors, an independent group of parents of young children with CP, as well as therapists who provide services to such children but were not a part of the study. As peer-reviewed manuscripts are accepted, these summaries are available at: <http://www.canchild.ca/en/ourresearch/moveplay.asp>. French versions of the summary have also been prepared.

#### Key Findings

Rehabilitation therapists and families suggest that these are the key findings of the Move & PLAY study:

- 1) The conceptual model developed for the study emphasizes a **broader perspective** when looking at a child with CP, extending beyond aspects of the child to the family (and their needs), as well as the health, recreation, and rehabilitation services the child receives (summary posted online).
- 2) All children with CP - even children classified in level I (that is, children who acquire the functional abilities of a child without CP at five years of age, but with some difficulties with movement speed and coordination) of the Gross Motor Function Classification System (GMFCS) - experience **remarkably more health conditions** than children without CP and many of these conditions impact daily life considerably. These need to be addressed in a timely manner, as the conditions present (summary posted online).

- 3) One of the key outcomes was the development of **shorter, very accurate measures**. A summary of shorter versions of the Gross Motor Function Measure is posted online, and abbreviated versions of measures of balance, endurance, and participation in recreation and self-care are forthcoming. Using shorter measures provides therapists with more time to assess other aspects of children and families that are important to them.
- 4) **Balance has the largest impact** on the group of primary impairments and can be improved with therapy. Better balance abilities are related to higher motor function and participation in self-care.
- 5) **Muscle strength** had the largest contribution to secondary impairments, and is most strongly related to motor function scores. Addressing muscle strength issues may **help children in their daily play activities**.
- 6) Services should also **support children's adaptive behaviour** to enhance motor function, self-care ability, participation in life activities and playfulness.
- 7) Parents of children with CP, especially parents of children with the greatest motor ability challenges (GMFCS level V), need **support for caregiving**. There needs to be more resources for families to help their children achieve the best possible self-care abilities.
- 8) Formal and informal **supports and interventions need to be individualized** so they are acceptable to each family's social and environmental culture.
- 9) All children, regardless of motor abilities, showed a **high level of enjoyment** as they participated in activities. A wide **range of supports may be needed** to help children with greater motor challenges achieve the best possible levels of participation in play.
- 10) Families need assistance accessing both **therapy and recreation programs** that incorporate muscle strengthening, flexibility, and cardiovascular exercises in the context of activities for children of all abilities.
- 11) There is a **need for coordinated care**, including monitoring children's health, and providing information to families. Service providers should make referrals to other appropriate health professionals as indicated.
- 12) **Addressing parents' concerns in intervention** is essential. There needs to be a shift in thinking from "fix the child" to "fix the environment".
- 13) Parents need to be **presented with choices** when it comes to care decisions. Parents need help to find resources for supports and expert information.

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

- Recognize the complexity of factors associated with a variety of child outcomes for young children with CP
- Recognize the challenge service providers experience in supporting children with CP and their families
- Ensure service providers have opportunities to be mentored appropriately to develop the necessary expertise to support children with CP and their families
- Provide services with both formal and informal supports
- Recognize the importance of indirect therapy time to access appropriate information and resources for children and families

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