



## Children's Participation in Self-Care and Ease of Care-giving for Parents

### Movement and Participation in Life Activities of Young Children Information for Families and Service Providers

#### The Move & PLAY study.....in brief:

**Who participated?** 430 preschool (age 18 months to 5 years) children with **Cerebral Palsy (CP)** and their families were recruited from many regions of Canada and the USA; all children had CP or problems with motor activities, **muscle tone** and **balance**.

**What did we do?** We focused on learning what helps children with CP progress in their ability to move around, take care of themselves (**self-care**: feeding, dressing, bathing) and **play**.

**What was our goal?** We wanted to find out what we can change about the way we help young children who need rehabilitation services, so we can focus on providing the services that are most beneficial.

**How did we do this?** We collected information about many characteristics of the child, the family, and the recreation and rehabilitation services they receive, during 3 sessions over a one-year period.

#### Looking at participation in self-care and ease of caregiving:

This report highlights the information we gathered about children's participation in self-care activities (such as eating, dressing, and bathing), and ease of caregiving for parents. We collected information about these activities at the 1<sup>st</sup> session, using a new measure developed by the research team. Information about the reliability and validity of this measure is provided in a supplementary file.

##### "Child Engagement in Daily Life" Measure

- 18 questions about many aspects of children's participation in daily life. Parents reported on: child's ability to do or help with **self-care** activities

##### "Ease of Caregiving for Children" Measure

- 12 questions on how easy is it for parents to take care of their child

We looked at the **effect of children's gender, age, and Gross Motor Function Classification System<sup>1</sup> (GMFCS)** level on children's participation in self-care, and ease of caregiving for parents. GMFCS has 5 levels of motor abilities; children in level I have the highest motor abilities, and children in level V the least motor abilities.

#### Why is it important to know about children's participation in self-care and ease of care-giving?

- Participation in self-care is one of the **primary activities** of young children
- Self-care is a **foundation to daily life**; a top priority of parents; and it encourages self-reliance in children
- Adults with disabilities tell us that abilities in self-care play a **key role** in their quality of life
- **Important goals** of rehabilitation services are to **promote** children's participation in activities of daily life and **support** families in caring for their children

#### What did we learn?

*Please keep in mind that these results are based on averages for the total group.  
Children are individuals and not all would fit the results described below.*

**Parent respondents:** The majority (92%) of parents who participated were mothers.

**Influence of Gender:** There was **no difference** between boys and girls in their ability to take care of self, or for ease of caregiving by parent.

*This is one of two summaries describing children's participation in daily life activities; please see the other summary titled "Children's Participation in Family Activities and Play" that will be posted on the website in the future.*

Definitions for words highlighted in blue ink can be found in our [Glossary](#).

Other summaries reporting the results of this study are available on the [Move & Play Study page](#) at [www.canchild.ca](http://www.canchild.ca)

## Self-care Abilities

- Scores were on a scale of 1 to 5 (**higher scores mean “better” abilities**)
- Older children were more advanced in their self-care abilities, however children with greater motor ability challenges (GMFCS levels IV and V) did not show higher scores with older ages
- Average score for all children was 2.6 ( **“needs constant help OR help for part of activity”**)
- GMFCS level had a significant effect: **children with higher motor abilities were more independent in self-care abilities**. Average scores ranged from 3.5 (needs some help; level I) to 1.3 (unable; level V); average for children in Levels II and III =2.7; level IV=2.2 (constant help)

## Ease of caregiving for parents:

- Scores were on a scale of 1 to 5 (**higher scores mean “easier” caregiving**)
- Average score for all was 3.7 (**“little to no difficulty”** for parents to help their children)
- Caregiving was easiest for parents of children with higher levels of motor ability (GMFCS Level I), and **most difficult for parents of children with lower levels of motor ability** (Levels IV and V). This was true for all ages

## What does this mean?

### Thoughts for families

- ◇ Therapists need to know about your child’s usual participation in self-care activities; this information is very useful when planning care that will be most helpful to your child
- ◇ Parents of children with limited motor ability should know that children may need support and adaptations to the environment to participate in self-care
- ◇ Parents might consider basing their expectations of self-care abilities on their children’s age and motor function abilities
- ◇ Talk to your therapist about any challenges you have when helping your child with daily activities

### Thoughts for service providers

- ◇ Children with CP demonstrated self-care abilities that were related to their age and level of motor ability
- ◇ A wide range of supports may be needed to help children with greater motor ability challenges (GMFCS levels IV and V) achieve the best possible self-care abilities
- ◇ Some parents may need support with caregiving tasks; parents of children with the greatest motor ability challenges (GMFCS level V) need the most support for caregiving
- ◇ Therapists have a role in providing supports and interventions to optimize children’s participation in their self-care and family’s ease of caregiving for their children

**Reference:** 1. Palisano RJ, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B: Development and validation of a Gross Motor Function Classification System for children with cerebral palsy. *Developmental Medicine and Child Neurology* 1997;39:214-223.

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For more details regarding Participation, please refer to our papers below.



**Understanding Determinants of Basic Motor Abilities, Self-care, and Play of Young Children with Cerebral Palsy**

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Chiarello LA, Palisano RJ, Westcott McCoy S, Bartlett DJ, Wood A, Chang H-J, Kan L-J, Avery L. Child Engagement in Daily Life: A measure of participation for young children with cerebral palsy. *Disability and Rehabilitation*. 2014; 36:1804-1816.

Ward KD, Chiarello LA, Bartlett DJ, Palisano RJ, Westcott McCoy S, Avery L. Ease of Caregiving for Children: A measure of parent perceptions of the physical demands of caregiving for young children with cerebral palsy. *Research in Developmental Disabilities*. 2014; 35:3403-3415.

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