



Family Life

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.

Learning about family life:

This report focuses on what parents told us about their families at the 2nd session (a telephone interview). We asked about many different things, for example: family activities, the supports that families have in caring for their children, and the home environment. We used **4 questionnaires** about family life:

(1) Family Environment Scale¹:

A **standardized measure**: **90 statements** (true or false) about many aspects of family functioning, for example: relationships, recreation and activities, conflict, organization, and beliefs. Examples of statements: “there is a feeling of togetherness in our family”; “family members often go to the library”.

(2) Family Expectations of Child:

Five questions about expectations parents have of their children; for example: to do the best they can, and to do all regular family activities, within their level of ability.

(3) Family Support to Child:

Six questions about how parents help their children to do self-care activities, play, and move around; for example: offering encouragement and recognizing accomplishments, and responding in a positive way to the child’s interests.

(4) Family Support Scale²

A standardized measure: **18 questions** about people and groups helpful to parents raising a young child with a disability: for example, immediate and extended family members, friends, co-workers, people in various community groups, and in health and education services.

Comparisons between families of children with and without CP:

- Small substudy of 110 families with preschool children who did not have CP or problems with movement
- We wanted to learn if family expectations and family support of children were similar or different between these 2 groups (i.e. compared 430 children with CP and 110 children without CP)

Why is it important to know about family life?

- We know that family environment and other family characteristics influence children’s development
- We wanted to understand what aspects of family support are most likely to promote beneficial outcomes for children

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

What did we learn?

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

We wanted to know if family characteristics were affected by the child's age, gender, and [Gross Motor Classification System](#)³ (GMFCS) level. GMFCS has 5 levels of motor abilities; children in level I have the highest motor abilities and children in level V have the least motor abilities.

We found that **age and gender did not have any effect** on these measures of family life.

Family Environment Scale:

- On average, families reported a healthy family environment
- Scores were similar for all families and the child's level of motor ability did not have an effect on scores

Family Expectations of Child:

- Scores were on a scale of 1 to 7 (1=not at all; 7= to a very great extent)
- On average, families reported that they had high expectations of their children; the average score was "6" (expectations were "to a great extent")
- Parent responses varied for children across some of the levels of the GMFCS. Parents reported expectations for children in level V that were slightly lower than for children in all other levels (average score was 5: "to a fairly great extent"). Some parents commented that their expectations were in line with their children's abilities. In other words, they usually did not expect their children to try things that were well beyond their abilities

Family Support to Child

- Scores were on a scale of 1 to 7 (1=not at all; 7= to a very great extent)
- Average score for all children was "6". This means that parents encouraged and supported their children "to a great extent", when helping them learn how to play, take care of themselves, and move around
- There were no meaningful differences in parent responses for children across all GMFCS levels

Family Support Scale

Parents noted which people or groups were available to them and rated the helpfulness of each of them. We looked at this information in 2 ways:

- defined 3 groups of supports: immediate family; "next circle of support" (e.g. friends); formal support groups/services; then rated the helpfulness of each group as well as the "average helpfulness" overall for all supports
- calculated the number of supports (people and/or groups) that were available and helpful to each family
- Scores were on a scale of 1 to 7 (1=not at all helpful; 7=extremely helpful)
- Average "helpfulness" scores for each group:
 - immediate family - 4 ("very helpful")
 - next circle of support - 3 ("generally helpful")
 - formal support groups - 4 ("very helpful")Average helpfulness score overall (all available supports) was 3 ("generally helpful").
- Average number of supports that were available and helpful to the families:
 - immediate family - 4 persons
 - next circle of support - 3 persons
 - formal support groups - 5 groupsAverage total number of supports was 11 persons or groups per family (range was 4-18).

- There were no meaningful differences in parent responses for children across all GMFCS levels; regardless of the child's motor abilities, parents reported receiving similar levels of help and support

Comparisons with families of children without CP

- Family expectations and support of children did not differ between families of children with or without CP. Most families had high expectations of their children, and supported their children to a great extent, while considering their child's abilities

What does this mean?

Thoughts for families

- ◇ It is important to advocate for the realization of the hopes and dreams that you have for your child
- ◇ Consider sharing information with service providers about your family's life and resources- this will help them provide individualized supports and interventions that are more meaningful to your family
- ◇ Ask service providers about options for formal sources of support that may be helpful to your family
- ◇ Discuss with service providers your expectations for your child and appropriate ways to provide support

Thoughts for service providers

- ◇ Acknowledge all families' strengths and their positive influence on children's development and function
- ◇ Ask families to share information about their daily life and about the people who are important to them
- ◇ Individualize formal and informal supports and interventions that relate and are acceptable to a family's social and environmental culture
- ◇ For families of children with limitations in self-mobility, provide suggestions for adapting expectations and supports, matched to the child's ability level

References:

1. Moos RH, Moos BS. *Family Environment Scale. Development, Applications, and Research*. 3rd edition. Palo Alto, CA: Mind Garden; 2002.
2. Dunst CJ, Jenkins V, Trivett CM. Measuring social support in families with young children with disabilities. IN *Supporting and Strengthening Families. Volume 1. Methods, Strategies, and Practices*. Dunst CJ, Trivette CM, Deal AG (Eds.). Cambridge, MA: Brookline Books; 1994: 152-160.
3. 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* 39:214-223, 1997

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For more details regarding Family Life, please refer to our paper: - LaForme Fiss A, Chiarello L, Bartlett D, Palisano R, Jeffries L, Almasri N. Family ecology of young children with cerebral palsy. *Child: Care, Health and Development*. 2014; 40:562-571 .



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

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