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Comparative study of home and community participation among children with and without cerebral palsy

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ABSTRACT

Background: Children with cerebral palsy (CP) are at increased risk of reduced participation. Parental evaluation of child's participation is often the decision-making factor in the process of special education and/or rehabilitation.

Aims: Examine and compare home and community participation of children with CP and typical development (TD) and the associations between their parents' desire for change and participation dimensions in both settings.

Methods and procedures: This cross-sectional study included a convenience sample of 110 children with CP (55% males; mean age 12.7 years) and 134 children with TD (49% males; mean age 12.1 years). The Participation and Environment Measure for Children and Youth (PEM-CY) was used.

Outcomes and results: Home and community participation and environmental supportiveness of children with CP were lower compared to children with TD ($p < .001$, family income controlled). The effect sizes indicated that there may be no clinically important difference in participation frequency. Parents of children with CP desired change if participation was less diverse at home, less frequent in the community, or if involvement was lower in both settings (environmental supportiveness and income controlled).

Conclusions and implications: At home, parents expressed a desire for change more intensely through the range of activities, while parents of children with TD emphasized participation frequency. In the community, parents of children with CP equally perceived participation diversity and focused more on frequency and involvement.

What this paper adds

This research expands the current knowledge on participation of children with cerebral palsy (CP) by exploring the association between dimensions of participation and additionally, confirming that their overall participation was lower in relation to the comparison group of children with typical development (TD). Effect sizes revealed the biggest differences in environmental supportiveness and involvement level both at home and in the community. Although statistically significantly lower in the group of children with CP, the frequency of home and community participation was comparable between two groups. However, the findings indicated that children with CP who did participate in some activities were involved in those activities at a similar frequency to children with TD, supporting the notion that the real difference was in diversity of participation, within the attendance construct. Parents of children with CP desired more change if participation was less diverse at home, less frequent in the community, or if

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involvement was lower in both settings. In summary, the results of this study documented that parents' satisfaction with the children's current participation varied across different settings in relation to three dimensions participation (range or diversity of activities, frequency, and involvement). The present study highlighted differences in parents' satisfaction with their children's participation and demonstrated that participation restrictions should not be related only to low frequency of attendance.

1. Introduction

Cerebral palsy (CP) is the most common group of permanent disorders of movement and posture, causing activity limitation attributed to non-progressive disturbances that occur in developing fetal or infant brain (Rosenbaum et al., 2007). CP affects 2–3 children per 1000 live births (Cans, 2000). The International Classification of Functioning, Disability and Health (ICF) defines participation as a person's "involvement in life situation" and participation restriction as "problems an individual may experience in involvement in life situations" (World Health Organization, 2001). The focus of participation is on everyday functioning and intersection between the individual and the environment. One of the ways to describe the essence of this complex and multidetermined concept is through two key elements: attendance and involvement. Attendance is expressed as frequency and/or the range or diversity of activities, whereas involvement is defined as subjective experience of participation while attending (2017, Imms et al., 2016). Numerous studies have shown that children with CP are at increased risk of reduced participation in terms of diversity, frequency, and involvement, both at home and in the community which they live in (Bedell et al., 2013; Engel-Yeger, Jarus, Anaby, & Law, 2009; Imms, Reilly, Carlin, & Dodd, 2008; Law et al., 2013; Majnemer et al., 2008; Majnemer, Shikako-Thomas, Schmitz, Shevell, & Lach, 2015; Mc Manus, Corcoran, & Perry, 2008; Michelsen et al., 2009; Parkes, McCullough, & Madden, 2010).

According to the ICF, the presence of restriction in participation should be "determined by comparing an individual's participation to that which is expected of an individual without disability in that culture or society" (World Health Organization, 2001). Research focusing on participation and participation restriction of children with developmental disabilities, including children with CP, has increased significantly over the past two decades. However, the differences in the parents' evaluation of participation between various settings have not been addressed in the previous studies. Particularly, it is not understood whether overall parental satisfaction with their child's current participation is associated with dimensions of participation, and if it is, in what way. This is important because families are increasingly encouraged to take an active role in health care, education, rehabilitation, professional training and employment of their child with physical disabilities (Darrah, Magil-Evans, & Adkins, 2002). Given that parents' reports are often a guide to decision-making for children (Davis, Mackinnon, & Waters, 2012), more comprehensive understanding is essential and required with regard to differences in the parents' subjective evaluation of participation between various settings, and in comparison to parents of children with typical development (hereinafter referred to as TD). In other words, if we seek to evaluate and explore the quality of participation by asking about the extent of the parents' satisfaction, then one of the first steps would involve examining the relationship with key dimensions of participation. It is noteworthy that the legal provisions regulating inclusive education in Serbia have not been fully implemented yet (Jovanovic-Popadic, 2016). The conditions for adequate reception of children with disabilities into the regular school system, related to attitudes towards persons with disabilities and towards educational inclusion, preparation of regular schools, support system and financing have not been met (Dimoski & Nikolić, 2015; Kovačević & Maćešić-Petrović, 2012; Mijatović, 2013). Therefore, it has been decided to focus on participation at home and in the community environment in this study.

This study is part of a larger research project focused on participation of children with CP living in Serbia. The research project that forms the empirical basis of this study is a cross-sectional and descriptive study of two groups of children. The purpose of this study is to explore the views of parents of children with CP and parents of children with TD about their child's home and community participation and overall supportiveness in each setting, as well as the relationships between dimensions of participation. In order to meet this objective, we have pursued the following aims: 1) examine home and community participation of children with CP, 2) examine the association between the number of activities done in each setting, frequency of participation and the child's involvement, and the parents' desire for change in their child's participation, and 3) draw comparisons with children with TD.

2. Method

2.1. Sample and procedure

Participants were recruited using the convenience sampling method. Sixty-five different health, educational and social welfare institutions, as well as national and local disability organizations and associations of persons with CP from 48 municipalities of Serbia were invited, and 35 (53.8%) of them gave permission for participation in our research. The participants were selected from their registers. Children with TD were recruited through regular schools, while children with CP were recruited mostly through special schools and special school services, hospitals and rehabilitation centers, as well as through several associations of persons with CP or associations of persons with disabilities. The general inclusion criteria were as follows: children of both genders, aged 7–18 years, residing with their families on the territory of the Republic of Serbia. In addition, children with TD had no history of psychological, neurological, motor or speech and language issues that might affect their participation, according to their parents' report. The inclusion criterion of the group of children with CP was the cerebral palsy diagnosis, according to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10; World Health Organization, 2004).

In the next step, 397 research invitations with the questionnaire package were distributed by regular mail. They included both a demographic and a participation questionnaire. The accompanying letter contained an introduction to and information about the

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