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Patterns and predictors of participation in leisure activities outside of school in children and adolescents with Cerebral Palsy

Egmar Longo ^a, Marta Badia ^{b,*}, Begoña M. Orgaz ^c

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ABSTRACT

This study analyzed the patterns and predictors of participation in leisure activities outside of school of Spanish children and adolescents with Cerebral Palsy (CP). Children and adolescents with CP (n = 199; 113 males and 86 females) participated in this cross-sectional study. Their mean age was 12.11 years (SD = 3.02; range 8–18 years), and they were evaluated using the Spanish version of the Children's Assessment of Participation and Enjoyment (CAPE). Means, standard deviations and percentages were used to characterize the profile of participation, and linear regression analyses were employed to assess associations between the variables (child, family and environmental factors) and the diversity, intensity and enjoyment of participation. Children and adolescents with CP reported low diversity and intensity of participation and high levels of enjoyment. Participation in leisure activities outside of school was determined more by child and environmental factors than by family ones.

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1. Introduction

Cerebral Palsy (CP) is the most common cause of disability in children, and it is estimated that there were 400,000 people living with CP in the European Union before its recent enlargement, with 10,000 new cases occurring each year (McManus et al., 2006). Because of their motor problems, children and adolescents with CP experience participation restrictions and limitations of physical activities (Donkervoort, Roebroeck, Wiegerink, van der Heijden-Maessen, & Stam, 2007; Imms, Reilly, Carlin, & Dodd, 2008).

Growing interest has emerged among rehabilitation professionals in moving beyond simply improving bodily functions and functional abilities in children with disabilities, and services now attempt to optimize social participation as one of the major goals (Hammal, Jarvis, & Colver, 2004; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001).

The International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) defines participation as involvement in life situations and defines environmental factors as the social, attitudinal and physical environments in which people live. When these factors have a positive influence on an individual's participation, they are called facilitators, and when they have a negative influence, they are called barriers (Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006).

^a INICO, Faculty of Psychology, University of Salamanca, Spanish Agency of International Cooperation – MAEC – AECID, Avda. de la Merced, 109-131, 37005 Salamanca, Spain

^b INICO, Faculty of Psychology, University of Salamanca, Avda. de la Merced, 109-131, 37005 Salamanca, Spain

^c Faculty of Psychology, University of Salamanca, Avda. de la Merced, 109-131, 37005 Salamanca, Spain

^{*} Corresponding author. Tel.: +34 923 29 46 95; fax: +34 923 29 46 85. E-mail address: badia@usal.es (M. Badia).

The UN Convention on the Rights of the Child, to which all European Union countries are signatories, states that disabled children should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community (article 23). The child shall not be denied the right, in community with other members of his or her group, to enjoy his or her own culture (article 30) (United Nations, 2006).

However, in comparison with peers without disabilities, adolescents and young adults with disabilities display less diverse participation, greater participation in passive recreational activities (such as watching television), and less social participation (King, Petrenchik, DeWit, McDougall, Hurley, & Law, 2010).

It is widely acknowledged that participation in leisure activities contributes to the physical, mental, and social health of individuals, families, and communities. Leisure has been defined as the time designated for freely chosen activities, performed when not involved in self-care, school or work, because they are enjoyable (Majnemer et al., 2010). Participation in leisure activities leads to positive self-esteem, a sense of competence, and higher academic achievement. In the appositive, low levels of participation at a young age can adversely impact motivation to participate at later ages, and the risk for developing obesity is higher among children who are physically inactive (Annesi, 2004; Kristensen et al., 2008; Parfitt & Eston, 2005).

It is important to understand the relative importance of the factors that may influence the leisure and recreation participation of children with physical disabilities and the paths by which these factors have their effects. Recent studies have highlighted several possible predictors of children's participation: environmental factors, such as physically accessible and welcoming environments; family factors, such as income and family functioning; and child factors, such as cognitive ability, preferences and social skills (King, Lawm, King, Rosenbaum, Kertoy, & Young, 2003; Shikako-Thomas, Majnemer, Law, & Lach, 2008).

In Spain, the latest official data indicate that there are 82,200 people with CP aged over 6 years, and approximately 2000 between 0 and 5 years (Instituto Nacional de Estadística, 2008). In Spain, models for the care of people with disabilities are not based on a medical model but instead are based on biopsychosocial models that orient services and public care for people with disabilities. For children with CP, it is vital to assess not only the child's disability but also the extent to which the child is able to and enjoys participating in meaningful domains, including leisure activities (Parush & Rihtman, 2008). In Spain, as in some other European countries, the US and Canada, rehabilitation services have considered other outcomes, such as participation and quality of life, because they are potentially modifiable variables.

The purpose of this study is to evaluate the patterns of participation in leisure activities outside of school of Spanish children and adolescents with CP, aged between 8 and 18 years. Specifically, this study has three objectives: (1) to describe comprehensively the leisure activities outside of school in which Spanish children and adolescents with CP participate (diversity), how often they participate (intensity) and whether they enjoy these activities; (2) to analyze the percentage of activities in which the children participate in each domain and the type of activity; and (3) to identify variables related to participation in leisure activities outside of school of children and adolescents with CP who live in Spain.

2. Methods

2.1. Participants

A cross-sectional analytical design was used. Children and adolescents with CP of any severity of motor function, aged between 8 and 18 years old, were recruited from 16 Associations Caring for People with Cerebral Palsy and Related Disabilities (ASPACEs) that were located in diverse regions of Spain.

One hundred and ninety nine children and adolescents participated. One hundred and thirteen were males (56.8%) and 86 were females (43.2%), with a mean age of 12.11 years (SD = 3.02, range 8–18 years). Of the total sample, 60.8% walked with or without support and 39.2% used a manual wheelchair or electric wheelchair. While 19.1% of the sample did not show intellectual impairment, 42.7% had severe impairment. Most children (72.4%) attended regular school. The characteristics of the family and context are shown in Table 1.

2.2. Measures

2.2.1. Spanish version of Children's Assessment of Participation and Enjoyment

The Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2007) was used to assess the profile of children's and adolescents' participation in leisure and recreation activities outside of mandated school activities. It is a reliable and valid self-report measure of participation for children and youth ages 6–21 that includes both formal and informal domains and five activity types: recreational, active physical, social, skill-based, and self-improvement activities (King, 2004; King et al., 2006).

The CAPE includes 55 activities and is completed as a questionnaire or by interview. The child is asked whether an activity was performed during the past 4 months (diversity), and if so, how often (intensity), with whom, where and how much the child enjoyed that activity (enjoyment of participation). This instrument provides three levels of scoring: (1) overall participation scores, (2) domain scores reflecting participation in formal (15 items) and informal (40 items) activities, and (3) scores reflecting participation in recreational (12 items), active physical (13 items), social (10 items), skill-based (10 items), and self-improvement (10 items) activity types.

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