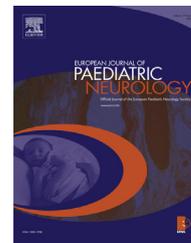




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## Original article

# European study of frequency of participation of adolescents with and without cerebral palsy



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## ABSTRACT

Children with cerebral palsy participate less in everyday activities than children in the general populations. During adolescence, rapid physical and psychological changes occur which may be more difficult for adolescents with impairments.

Within the European SPARCLE project we measured frequency of participation of adolescents with cerebral palsy by administering the Questionnaire of Young People's Participation to 667 adolescents with cerebral palsy or their parents from nine European regions and to 4666 adolescents from the corresponding general populations. Domains and single items were analysed using respectively linear and logistic regression.

Adolescents with cerebral palsy spent less time with friends and had less autonomy in their daily life than adolescents in the general populations. Adolescents with cerebral palsy participated much less in sport but played electronic games at least as often as adolescents in the general populations. Severity of motor and intellectual impairment had a significant impact on frequency of participation, the more severely impaired being more disadvantaged. Adolescents with an only slight impairment participated in some domains as often as adolescents in the general populations. Regional variation existed. For example adolescents with cerebral palsy in central Italy were most disadvantaged according to

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decisional autonomy, while adolescents with cerebral palsy in east Denmark and northern England played sports as often as their general populations.

Participation is an important health outcome. Personal and environmental predictors of participation of adolescents with cerebral palsy need to be identified in order to design interventions directed to such predictors; and in order to inform the content of services.

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## 1. Introduction

Social and physical participation and deciding how to spend your life are important for all people, including children and adolescents with and without disabilities. Participation is defined by the ICF–CY<sup>1</sup> as ‘involvement in life situations’ but is nevertheless still being refined in terms of conceptualisation and measurement.<sup>2–5</sup> It is generally regarded as consisting of components such as school life, family and peer group activities and engagement in work and leisure. Participation is amenable to intervention and is an important health outcome for intervention research.

Children with cerebral palsy (CP) aged 8–12 years participate less in everyday activities than children in the general populations.<sup>6,7</sup> Participation of children with CP varies considerably between countries.<sup>8</sup> The environment of children with CP also varies considerably between countries<sup>9</sup> and higher participation is known to be associated with the availability of a facilitatory environment.<sup>10</sup>

Adolescence is a critical developmental period that forms the basis of social integration in adulthood. Change and adjustment may be more difficult for adolescents with impairments and may result in reduced adult participation. Indeed, adults with CP are disadvantaged according to employment and cohabitation.<sup>11–14</sup>

Few epidemiological studies have focused on participation of adolescents with CP and suitable measurement instruments are lacking.<sup>15,16</sup> Participation has a variety of dimensions; some instruments to measure participation capture whether or not the individual participates in an activity and if so the level of difficulty experienced,<sup>17</sup> while others measure frequency of or enjoyment with participation.<sup>18</sup> Comparative studies of frequency of participation in adolescents with and without impairment may yield insights into where further work is needed to equalise these groups.

There is a lower frequency of participation among adolescents with CP, compared with adolescents without CP.<sup>19–21</sup> Severity of impairments is seldom taken into account and if so only motor impairment is considered.<sup>21,22</sup> Adolescents unable to self-complete are often excluded.<sup>20,23</sup> In addition many studies target only specific areas of participation, for example leisure or physical activities<sup>24</sup> or include younger children and do not ask about typical adolescent activities like online communication or spending time with a boy- or girlfriend.<sup>21</sup>

Studying inter-country levels of participation in adolescence has the potential to identify regions with more or less facilitatory environments. This paper aims to compare

frequency of participation in everyday life of adolescents across the spectrum of severity of CP and adolescents in the general population in nine European regions. We use QYPP (Questionnaire of Young Peoples Participation) – a new instrument of frequency of participation capturing participation in typical adolescent activities at home, school or work, and during leisure.<sup>16</sup> It was developed by interviews with adolescents with and without CP as well as with parents of adolescents with CP not able to self-complete.

## 2. Method

This study is part of the European multicentre SPARCLE study which examines the quality of life and participation of children and adolescents with cerebral palsy. Full details are published<sup>25,26</sup> and key elements are summarised below.

Eight European regions with population-based registers of children with CP participated: north England, Northern Ireland, southwest Ireland, southwest France, southeast France, central Italy, west Sweden and east Denmark. A further region in northwest Germany recruited children from multiple sources; their age, gender, and levels of impairment were similar to those of children in the population-based registers, although German adolescents were interviewed at a slightly younger age.<sup>27,28</sup>

### 2.1. Participants

Children with CP, born 1991–97, were randomly sampled from the registers. The 818 children who entered SPARCLE1 were followed up in 2009/2010 aged 13–17 years; 594 (73%) agreed to participate and the overall participation rate from sampling in registries to follow-up in adolescence was 51%. In order to maintain statistical power for cross-sectional analyses and possible follow-up to adulthood, SPARCLE2 additionally sampled from adolescents who were eligible for SPARCLE1 but who had not participated in SPARCLE1; 73 agreed to participate. Hence 667 adolescents were included in SPARCLE2 and their characteristics are shown in Table 1. Only cross-sectional data from adolescents are analysed in this paper.

For comparison, adolescents in the same age range as those in SPARCLE2 were recruited from the general populations from schools in the uptake area of each cerebral palsy register. Schools were randomly sampled from lists of all schools in the areas. In total 52 schools (4666 adolescents) participated. Recruitment of schools, response rates and characteristics of adolescents in the general populations are shown in Table 2.

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