



## Research Paper

# How available to European children and young people with cerebral palsy are features of their environment that they need?



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## ABSTRACT

**Background:** The UN Convention on the Rights of Persons with Disabilities requires accessibility to the physical and social environments. However, individuals with cerebral palsy (CP) have many difficulties in accessing the environment they need for functional independence and social inclusion.

**Aims:** To examine the availability of environmental features which children with CP need for optimal participation, and whether availability changed for them between ages 8–12 and 13–17 years.

**Methods:** The sample is the 594 children with CP, born 31/07/1991–01/04/1997, who took part in the SPARCLE study at age 8–12 (SPARCLE 1) and again at 13–17 years (SPARCLE 2). Participants were randomly sampled from population registers of children with CP in eight European regions; one further region recruited from multiple sources. Data about environment were captured with the European Child Environment Questionnaire (60 items). Differences in availability of environmental features between childhood and adolescence were assessed using McNemar's test; differences between regions were assessed by ranking regions. Differences in availability between regions were assessed by ranking regions.

**Results:** For seven environmental features significantly ( $p < 0.01$ ) fewer individuals needed the feature in SPARCLE 2 than in SPARCLE 1, whilst for two features more individuals needed the feature. Nine features in SPARCLE 1 and six features in SPARCLE 2 were available to less than half the participants who needed them. Eight features showed significantly ( $p < 0.01$ ) higher availability in SPARCLE 2 than in SPARCLE 1 (enlarged rooms, adapted toilet, modified kitchen and hoists at home, adapted toilets and lifts at school, an adequate vehicle, grants for home modifications) while none showed significantly lower availability. The relative rankings of the better and less good regions persisted from the age 8–12 year age group to the 13–17 year age group.

**Conclusions:** Needed environmental features are unavailable to many children at ages 8–12 and 13–17 years. This lack of availability is more pronounced in some regions than others, which probably results from their policy, legislative and statutory frameworks.

## What this paper adds?

- Many children and young people with cerebral palsy do not have available to them the environmental features they need to

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participate fully; both at ages 8–12 years and 13–17 years

- For instance, nine features in SPARCLE 1 and six features in SPARCLE 2 were available to less than half the children who needed them.
- It was encouraging that there was higher availability in SPARCLE 2 for: Enlarged rooms, adapted toilet, modified kitchen and hoists at home, adapted toilets and lifts at school, an adequate vehicle, grants for home modifications.
- Striking differences between European regions in the availability of needed environmental features had been recognised for children with CP. This study shows that this variation persists into adolescence and that the relative rankings of the better and less good regions were very similar in both age groups.

## 1. Introduction

Article 9 of the 2006 UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) requires: “States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.” Such obligations can be considered within the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), whose objective is to provide a framework for describing and organising information on functioning and disability using a unified and standardized language (World Health Organization, 2007). It conceptualises a person's level of functioning as a dynamic interaction between health conditions, environmental factors, and personal factors. Article 9 is also consistent with the social model of disability (Oliver, 1990), which proposes that disability is caused by the way society is organized, rather than by a person's impairment or difference. To address Article 9, barriers that restrict life choices for disabled people must be removed so that people with disability can be independent and equal in society, with choice and control over their lives.

For children and youth with disabilities, every domain of the environment in the ICF is associated with participation (Anaby et al., 2013; Colver et al., 2012; Willis et al., 2016). The most common facilitators are social support of family and friends and geographic location. The most common barriers are attitudes, physical environment, transportation, policies, and lack of support from staff of service providers (Anaby et al., 2013).

Individuals with cerebral palsy (CP) may have many difficulties in accessing the environment which reduce their functional independence and social inclusion (Colver et al., 2012; Fauconnier et al., 2009; Michelsen et al., 2009; Michelsen et al., 2014). The SPARCLE 1 study, in which European children with CP were visited at age 8–12 years, found that children with more impaired walking ability had less access to the physical environment, transport and social support they needed than those with less severe impairment. They also experienced less favourable attitudes from family and friends. However, attitudes of teachers and therapists were similar for children with all levels of impairment. The availability of needed features, across children with all severities of impairment, showed significant variation between European regions (Colver et al., 2011).

Children in the SPARCLE 1 cohort were visited again aged 13–17 years (SPARCLE 2). We are not aware of any papers that have examined longitudinal change in the availability of needed environmental factors. We therefore aim in this paper to examine the availability of needed environmental features for young people with CP at 13–17 years and whether availability changed between 8–12 and 13–17 years.

## 2. Methods

### 2.1. Setting and participants

This work is part of the SPARCLE project, which studies the participation and quality of life of children and adolescents with CP in Europe. The sample for this study is the 594 children with CP who took part in both SPARCLE 1 and 2. They were born between 31 st July 1991 and 1 st April 1997, and were randomly sampled from population registers of children with CP in eight European regions (southeast France, southwest France, southwest Ireland, west Sweden, north England, Northern Ireland, east Denmark, and central Italy); one further region, northwest Germany, recruited from multiple sources.

The overall design of the project, including sample size calculations, is described in previous papers (Colver & Dickinson, 2010; Colver & SPARCLE Group, 2006).

Analysis of drop-out has been reported (Dickinson et al., 2012). In summary, of the 818 families who participated in SPARCLE1, 594 (73%) participated in SPARCLE2. The significant predictors of drop-out were parental education and stress, family structure and region. The main causes of drop-out were death (32), moved out of region (13), or could not be traced (51).

### 2.2. Measures

Data about the features of the environment which individuals needed to optimise their participation were captured with the parent-reported European Child Environment Questionnaire (ECEQ). This questionnaire has 60 items, each of which asks about a feature in the physical, social, or attitudinal environment of children (Dickinson, Colver, & SPARCLE Group, 2011). In SPARCLE 1 the items yielded nine domains: physical environment in the home, school and community; transport; social support in the home and community; and attitudes of family and friends, teachers and therapists, and classmates. However, the scoring of these domains applied only to SPARCLE 1 and we have not been able identify a scoring metric which is generalisable. In this paper we retain the

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