

ORIGINAL ARTICLE: RESEARCH

Access of children with cerebral palsy to the physical, social and attitudinal environment they need: a cross-sectional European study

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Accepted April 2010

Abstract

Purpose. The UN Convention on the Rights of Persons with Disabilities requires states 'to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, transportation, information and communications.' We explored whether this convention was respected for disabled children in Europe.

Method. One thousand one-hundred and seventy-four children aged 8-12 years were randomly selected from populationbased registers of children with cerebral palsy in eight European regions. 743 children joined the study; one further region recruited 75 children from multiple sources. Researchers visited these 818 children and administered the European Child Environment Questionnaire, which records parents' perceptions of availability of the physical, social and attitudinal environment needed in home, school and community. Multilevel, multivariable regression related child access on these domains to their impairments and socio-demographic characteristics.

Results. Children with more impaired walking ability had less access to the physical environment, transport and social support they needed than other children. 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 access of children, across all impairment severities, to their needed environment showed significant variation between regions ($p \le 0.0001$), some regions consistently providing better access on most or all domains.

Conclusion. European states need to substantially improve environmental access for disabled children in order to meet their obligations under UN Conventions. In some regions, many environmental factors should and realistically could be changed. Legislation and regulation should be directed to making this happen. Local environmental planners and health and social service providers should listen carefully to parents to address mismatches between policy intentions and parental experience.

Keywords: Cerebral palsy, environment, children

Introduction

Article 13 of the 2006 UN Convention on the Rights of Persons with Disabilities asserts the obligation of states 'to ensure to persons with disabilities access, on an equal basis with others, the physical environment, transportation,

information and communications' [1]. Such obligations are consistent with the social model of disability [2] and the International Classification of Functioning, Disability and Health [3], both of which consider disability to result from the interaction between a person's intrinsic impairment and their physical, social and attitudinal environment

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rather than as something that resides in the individual.

This article assesses progress towards these goals for children with cerebral palsy living in different European regions, using a recently developed instrument to capture the social, physical and attitudinal environment of disabled children described in the preceding companion paper [companion paper referencel.

Methods

Participants and procedures

The study is part of a wider study, SPARCLE, whose protocol, sampling strategy, participation rates and potential for bias have been reported in detail previously [4–6].

Briefly, 1174 children aged 8-12 years were randomly selected from population-based registers of children with cerebral palsy in eight European regions. Seven hundred and forty-three children joined the study; one further region recruited 75 children from multiple sources. Researchers visited these 818 families and, amongst a number of questionnaires, administered the European Child Environment Questionnaire (ECEQ) which covers the physical, social and attitudinal environmental features (EFs) likely to be needed by the child. The development of the ECEQ is described in the companion paper in this issue [companion paper reference]. Parents are asked if each EF is available or not. For example, a typical question is 'Are there ramps for your child to use in public places?' Possible responses are 'Mostly or usually yes' and 'Mostly or usually no.' For items about the physical environment and social support, response 'Not needed' is also allowed; other items were assumed to be essential. Factor analysis resulted in an empirical grouping of 51 ECEQ items into nine domains [companion paper reference] which are summarised in Table I.

Walking ability was assessed using the five categories of the gross motor function classification system (GMFCS). IQ was classified in three categories: > 70, 50-70, < 50 according to an IO assessment if one was available in the previous year or, if not, an algorithm based on responses by parents to the assistance the child needs in school and the extent to which the child's ability to understand ideas and develop friendships compared to children of similar age or much younger children. Communication ability was categorised (see Table II) on the basis of parents' reports. Type of cerebral palsy was available from the register.

Table I. Items and domains in ECEO, as indicated by factor analysis.

Physical environment

Home

Walking aids

Communication aids at home

Adapted toilet at home

Hoists at home

Enlarged rooms at home

Modified kitchen at home

School

Ramps at school

Communication aids at school

Adapted toilets at school

Lifts at school

Community

Adequate vehicle

Lifts in public places

Suitable doorways in public places

Accessible car parking

Adapted toilets in public places

Room in public places to move around

Ramps in public places

Smooth pavements in town or village centre

Transport

Accessible taxis

Accessible train services

Adequate bus service

Accessible buses

Social support

Home

Receive grants for equipment

Helper or assistant at home

Receive grants for home modifications

Receive grants for holidays

Information about financial benefits

Community

Social services co-ordinate work well

Child looked after elsewhere for few days

People in public places have positive attitude towards child

Child receives physical help from people in public places

Health service staff co-ordinate work well

Parent support groups in area

Counselling available

Suitable leisure facilities

Attitudes

Family and friends

Wider family and friends have positive attitude towards child

Child allowed extra time at home

Emotional support from wider family/friends

Child encouraged to reach potential from wider family/friends

Physical help from wider family/friends

Family/friends look after child for a few hours

Teachers and therapists

Special staff help child in school

Child encouraged to reach potential from teachers/therapists

Child receives emotional support from teachers/therapists

Child has school placement s/he needs

Teachers/doctors listen to your views

Child allowed extra time at school

Teachers have understanding of medical condition

Classmates

Classmates have positive attitude towards child

Child receives emotional support from classmates

Child encouraged to reach potential from classmates

Items are ordered from the most to the least widely available in each domain.



Table II. Median and inter-quartile range (IOR) of scores for child access on each domain.

		vithout limitation GMFCS* I)		with limitation FCS* II & III)		able to walk FCS* IV & V)
	Median	(IQR)	Median	(IQR)	Median	(IQR)
Physical environment						
Home	0.98	(0.91 to 1.22)	0.79	(-0.76 to 0.98)	-0.76	(-1.95 to 0.79)
School	0.33	(0.27 to 0.41)	0.27	(-0.32 to 0.37)	0.32	(0.25 to 0.40)
Community	1.37	(0.72 to 1.54)	0.13	(-1.14 to 1.34)	-0.97	(-1.92 to 0.04)
Transport	0.93	(0.65 to 1.20)	0.82	(-1.30 to 0.94)	-0.11	(-2.30 to 0.93)
Social support						
Home	0.82	(0.10 to 0.98)	0.06	(-0.61 to 0.48)	-0.32	(-0.89 to 0.12)
Community	0.49	(-0.09 to 0.96)	-0.13	(-0.62 to 0.38)	-0.25	(-0.86 to 0.28)
Attitudes						
Family and friends	0.84	(-0.23 to 0.95)	0.74	(-0.63 to 0.90)	-0.29	(-1.45 to 0.84)
Teachers and therapists	0.70	(-1.11 to 0.79)	0.70	(-0.96 to 0.79)	0.70	(-0.36 to 0.79)
Classmates	1.01	(-1.37 to 1.28)	1.01	(-1.44 to 1.24)	0.93	(-1.44 to 1.28)

^{*}Gross Motor Function Classification System.

Higher scores indicate higher access. Child access is not adjusted for any covariates

Statistical methods

We wanted to assess lack of access to needed EFs. Therefore, if an EF was needed but not available, access was scored as 1; otherwise (i.e., EF not needed or needed and available) access was scored as 0.

We assumed that access within each domain could be summarised by a single factor that was not directly observed but which influenced the parents' responses to the items [7]. We refer to this factor as child environmental access (or briefly child access) on each domain. We estimated its magnitude and its association with covariates - socio-demographic characteristics and impairment, categorised as reported previously [5,6] - using a multilevel, multivariable, latent regression Rasch model that allowed for clustering of children within regions (see Equations (1) and (2) in Statistical Appendix of companion paper [companion paper reference]).

Univariate analyses were first performed, considering each covariate in turn. Forwards stepwise regression followed by backwards steps was then used to select covariates to enter into the multivariable model. To lessen the probability of chance findings due to multiple hypothesis testing, the p-value for entry and removal of covariates was set at 0.01. The final models excluded children with missing data on included covariates. We estimated the significance of heterogeneity between regions by comparing the final multilevel, multivariable model with a similar model that did not allow for clustering within regions.

Odds ratios (ORs) and their 95% confidence intervals (CIs) are presented. For each type of impairment, the reference group is the category of children who are least impaired. For example, in Table II, in the domain of the physical environment at home, an odds ratio of 0.07 for children with gross

motor function V (Unable to walk, severely limited self-mobility) indicates that children with that level of impairment have 0.07 times the odds of having access to any EF in that domain compared to children with gross motor function I (Walks and climbs stairs, without limitation). We report the proportion of the total residual variance that is between regions (the intra-cluster correlation coefficient). We noted the percentage reduction in deviance due to (i) covariates and (ii) clustering within regions (deviance in binary models is analogous to variance in continuous models).

Statistical analysis was performed using the gllamm suite of programs in Stata 10 [7].

Ethics approval and consent

Ethics Committee approval was obtained in each country. All parents gave written consent. All children with sufficient cognitive capacity gave written consent or communicated consent if unable to write.

Results

The distribution of scores for child access on each domain is presented in Table II by level of walking ability. Children with more impaired walking ability tended to have less access on all domains except the domain of attitudes of teachers and therapists. All the attitudinal domains showed a ceiling effect: most children had scores close to the maximum.

Table III summarises the final multivariable models. Children with more impaired walking generally had significantly less access than less impaired children to aspects of the physical



Table III. Odds ratios from multilevel, multivariable regression models, relating child access on each domain to the child's impairments and socio-demographic characteristics.

			Physic	Physical environment	+		I	Transport		Social s	Social support				Attitudes		
		Ноте		School	Co	Community				Ноте	Š	Community	,	Family and friends	Teachers and therapists	0 1	Class- mates
u		807		818		817		818		813		817		818	818		813
p for heterogeneity between regions		< 0.0001		< 0.0001		< 0.0001		< 0.0001		< 0.0001		< 0.0001		0.0001	< 0.0001		0.0001
Intra-class correlation coefficient**		0.16		0.21		0.16		0.18		0.18		0.21		0.07	0.09		0.08
	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR* (95% CI)	OR*	(95% CI)
Impairments Gross motor function I Walks and climbs stairs, without	1.00	1	1.00	,	1.00	ı	1.00	ı	1.00	ı	1.00	1	1.00	ı			
limitation II Walks inside III Walks with assistive	0.27	(0.15 to 0.47) (0.04 to 0.11)	0.24	(0.13 to 0.45) (0.08 to 0.28)	0.24	(0.17 to 0.36) (0.05 to 0.12)	0.42	(0.22 to 0.81) (0.04 to 0.14)	0.36	(0.26 to 0.50) (0.17 to 0.33)	0.44	(0.34 to 0.58) (0.26 to 0.49)	0.47	(0.29 to 0.76) (0.24 to 0.63)			
devices IV Unable to walk, limited	0.04	(0.02 to 0.06)	0.13	(0.07 to 0.24)	0.05	(0.03 to 0.08)	0.05	(0.03 to 0.11)	0.18	(0.12 to 0.27)	0.34	(0.24 to 0.47)	0.22	(0.13 to 0.36)			
self-mobility V Unable to walk, severely limited self-mobility Intellectual	0.07	(0.04 to 0.12)	0.34	(0.17 to 0.66)	0.06	(0.04 to 0.09)	0.07	(0.04 to 0.14)	0.23	(0.16 to 0.34)	0.37	(0.25 to 0.54)	0.19	(0. 12 to 0.30)			
impairment > 70 50-70 < 550-70	1.00 0.54 0.51	- (0.36 to 0.81) (0.34 to 0.77)							1.00 0.66 0.67	- (0.49 to 0.88) (0.50 to 0.91)						1.00 0.40 0.18	- (0.18 to 0.86) (0.09 to 0.38)
Communication Normal speech Difficulty but uses											1.00	- (0.48 to 0.81)					
speech Uses non-speech for formal											0.65	(0.47 to 0.90)					
communication No formal communication Type of cerebral											0.67	(0.47 to 0.96)					
Spassy Spassic unilateral Spassic bilateral Dyskinetic Ataxic					1.00 0.52 0.54 0.55	- (0.38 to 0.71) (0.35 to 0.84) (0.29 to 1.06)											
																	(continued)



-(1.27 to 2.42)

1.00

(95% CI) 0.0001 0.08 813 Class-mates OR^* (95% CI) < 0.0001 0.09 and therapists Teachers Attitudes OR^* (95% CI) 0.0001 0.07 friends Family and OR^{\star} (95% CI) < 0.0001 Community 0.21 817 Social support OR^* (95% CI) < 0.0001 Table III. (Continued). \mathbf{OR}^{\star} < 0.0001 (95% CI) 0.18 < 0.0001 (95% CI) 0.16 Community OR^* Physical environment (95% CI) < 0.0001 0.21 OR^* (95% CI) < 0.0001 0.16 807 Socio-demographic characteristics OR^{\star} p for heterogeneity between regions Intra-class correlation coefficient**

Desented employment	ner m	3
1 arcura curprovincin		
At least one parent works	1.00	1
full time professionally		
At least one parent	0.65	0.65 (0.45 to 0.94)
works full time		
non-professionally		
One parent works	0.43	0.43 (0.24 to 0.79)
part-time		
Neither parent works	0.85	0.85 (0.50 to 1.43)
Gender		



^{*}Odds ratios are from latent regression Rasch models. **The intra-class correlation coefficient is the proportion of the residual variance that is between regions.

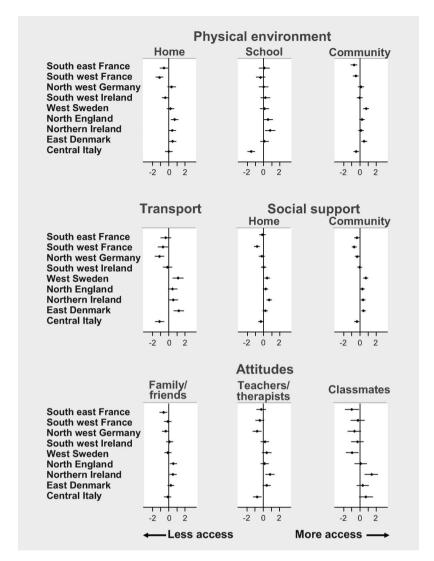


Figure 1. Mean level (with 95% confidence intervals) of child access in each region, adjusted for impairment and socio-demographic characteristics. Higher scores indicate better access. Mean adjusted child access is zero and each unit is one standard deviation of residual variation between children.

environment, transport and social support that they needed at home, at school and in the community. For example, ORs comparing access of the most impaired and least impaired children to the physical environment and social support in the home were 0.07 (95%CI: 0.04-0.12) and 0.23 (95%CI: 0.16-0.34) respectively, with similar ORs for the physical environment and social support in the community. Likewise, children with more impaired walking experienced less favourable attitudes among family and friends. Additionally, children with greater intellectual impairment tended to have less access to the physical and social support they needed at home; children with bilateral cerebral palsy had less access to the physical environment in the community; and children with communication difficulties had less access to the social support they needed in the community. Attitudes of teachers and therapists did not a show significant association with any

impairment. Attitudes of classmates tended to be less favourable towards children with greater intellectual impairment. Few socio-demographic characteristics were significantly associated with access: boys experienced less favourable attitudes from family and friends; children with at least one parent working full-time professionally and children with neither parent working had higher levels of access to the physical environment than other children.

All environmental domains showed significant variation between regions ($p \le 0.0001$) (see Figure 1). For all domains, the average level of access of children in southwest France was below the overall mean for all regions combined; the average access in southeast France was below the overall mean on all domains except the physical environment at school. In contrast, access of children in north England, Northern Ireland and east Denmark was above the overall mean on all domains. Nevertheless, the



variation in attitudes between regions was between 7 and 9% of the overall variation in attitudes; and the variation between regions for physical and social support domains was between 16 and 21% of the total variation (see intra-class correlation coefficient in Table III). Analysis of change of deviance showed that for all domains, more variation was explained by impairments than by region.

Discussion

Summary of main findings

Children with severely impaired walking ability had, on average, a much lower level of access than less impaired children to aspects of the physical environment, transport and social support that they needed in home, school and community; and they generally experienced less favourable attitudes among family and friends. However, they did not experience less favourable attitudes from teachers and therapists. While it may not be surprising that the more impaired children, who are likely to have more complex needs, have less access to what they need, this does not meet the aspirations set out in the UN Convention on the Rights of Persons with Disabilities [1]. In a society that met its obligations under that convention, children's access to needed EFs would show no relationship with the child's type or severity of impairment.

After allowing for impairment, children's environmental access showed significant variation between regions ($p \le 0.0001$), with some regions consistently providing better access on most or all environmental domains and some consistently providing poorer access.

Strengths and weaknesses of study

The participants were sampled from children with cerebral palsy in nine defined geographic areas, eight of which had population-based registers. Although non-response by families of children with cerebral palsy was 37%, this is typical of surveys that target specific families and conduct face-to-face interviews [5]. To minimise the risk of spurious differences between regions, interviewers were trained together at dedicated workshops [4].

The face validity of ECEQ is strong: preliminary qualitative studies - a literature review [8], in depth interviews [9] and focus group work with parents in the participating European regions [10] - were followed by rigorous statistical modelling to group EFs into meaningful domains [companion paper reference]. Our results showed very marked trends of less access among more severely impaired children.

As Whiteneck discusses [11], conceptualising and measuring the environment still needs much refinement. The ECEQ captures the family's perception of where the environment needs to be or has been modified for their child - an individualised, local analysis of child-environment interaction. However, Local Government may need to introduce a variety of environmental adjustments likely to be helpful for all disabled individuals in a locality and therefore requires an instrument which is more objective in its assessment of the environment. But such an instrument could not capture the proportion of disabled people with the adjustments they need. For example, possession of assistive devices does not mean they are needed, as many such devices are not used [12,13].

Related studies

In adults after spinal cord injury [14] and children with physical disabilities [15] more environmental barriers were reported by individuals with more severe impairment; both studies using the CHIEF instrument [16,17] which examines barriers, not facilitators. We found similar results using the ECEQ instrument which also takes account of the facilitation that results from having available what is needed.

We are not aware of any other studies that have examined variation in environmental availability between regions or countries.

Implications

There are three levels at which the variation in environmental access between regions might be explained. Firstly, it may vary because of different national policies, legislation and regulations. We have documented these in a report in two volumes [18,19]. For example, Denmark has a public system of after-school clubs, attended every day by most children up to age 12, whether disabled or not. All countries in the SPARCLE study make arrangements for adapted vehicles to take a child to and from school but in Denmark, Sweden and increasingly in Germany such transport is more widely provided to include taking children to after-school clubs and other social events. Secondly, children's environmental access may vary because of the extent to which the region implements national policy. Even if a region is attempting to implement national policy this may not benefit every child. For example, a region may require its taxis to have facilities for wheelchairs but this is of little benefit if a taxi cannot be booked at short notice or cannot pick up from remoter areas or if the driver is not trained to handle wheelchairs.



Thirdly, parents in different regions may view the environment differently. In some regions parents may have greater expectations of the environment and report unmet need more readily, or may be less aware of what is actually available.

In an earlier article, we showed that participation of children with cerebral palsy in everyday activities also varies systematically between regions [20]. We now need to model the relationship between participation and the environment, in order to assess the extent to which environmental variation can explain this regional variation in participation.

States should improve environmental access for children with impairments, especially those with severe impairments. The variation between regions in the availability of the needed environment implies that in some regions, many environmental factors should and realistically could be changed. Legislation and regulation should be directed to making this happen. Local environmental planners and health and social service providers should listen carefully to parents to address mismatches between policy intentions and parental experience.

Acknowledgements

The authors are grateful to the families who participated in SPARCLE and to the study research associates - Kerry Anderson, Barbara Caravale, Malin Carlsson, Eva Lise Eriksen, Delphine Fenieys, Bettina Gehring, Louise Gibson, Heidi Kiecksee, Ann Madden and Ondine Pez - for their enthusiasm and dedication to contacting families and collecting high quality data. The study was funded by the European Union Research Framework 5 Programme - Grant number QLG5-CT-2002-00636. The German region ioined later, funded by Bundesministerium für Gesundheit/German Ministry of Health (GRR-58640-2/ 14) and Stiftung für das Behinderte Kind/Foundation for the Disabled Child. The funders had no role in the study design; collection, analysis and interpretation of data; writing of the report or decision to submit for publication.

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