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RESEARCH PAPER

Quantifying the physical, social and attitudinal environment of children with cerebral palsy

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Abstract

Purpose. To develop an instrument to represent the availability of needed environmental features (EFs) in the physical, social and attitudinal environment of home, school and community for children with cerebral palsy.

Method. Following a literature review and qualitative studies, the European Child Environment Questionnaire (ECEQ) was developed to capture whether EFs needed by children with cerebral palsy were available to them: 24, 24 and 12 items related to the physical, social and attitudinal environments, respectively. The ECEQ was administered to parents of 818 children with cerebral palsy aged 8–12 years, in seven European countries. A domain structure was developed using factor analysis.

Results. Parents responded to 98% of items. Seven items were omitted from statistical models as the EFs they referred to were available to most children who needed them; two items were omitted as they did not fit well into plausible domains. The final domains, based on 51 items, were: Transport, Physical – home, Physical – community, Physical – school, Social support – home, Social support – community, Attitudes – family and friends, Attitudes – teachers and therapists, Attitudes – classmates.

Conclusion. ECEQ was acceptable to parents and can be used to assess both the access children with cerebral palsy have to the EFs that they need and how available individual EFs are.

Keywords: *Environment, children, cerebral palsy*

Introduction

Article 13 of the 2006 UN Convention on the Rights of Persons with Disabilities [1] asserts the obligation of states 'to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications.' The International Classification of Functioning, Disability and Health [2] considers disability to result from an interaction between a person's intrinsic impairment and their physical, social and attitudinal environment; this is consistent with the social model of disability [3]. It is therefore of interest to develop measures of the availability to disabled people of the environmental features (EFs) that they need.

Instruments have been developed to summarise quantitatively the environmental needs and level of access of disabled adults. The CHIEF instrument [4,5] has been used to model the relationship of environment to quality of life and participation in everyday activities [6]. The FABS/M was developed specifically for people with mobility limitations [7]. Specialised tools have been developed to quantify accessibility of the housing environment [8], urban public bus services [9] and fitness and recreation environments [10].

However, work examining the environment of disabled children is sparse and has focused largely on instruments developed for planning support for children in their school setting [11,12] or for clinical assessment, treatment planning and evaluation [13].

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The CASE instrument [14] was developed primarily to identify factors associated with the participation in everyday activities of children with acquired brain injury. A measure of the quality of the environment of adults [15] has been developed and subsequently adapted for children [16], but we are not aware of reports of either measure being used.

The study SPARCLE [17] examines, within the conceptual framework of the social model of disability, how the quality of life and participation of children with cerebral palsy relate to their environment across Europe. It required the development of an instrument to assess the social, physical and attitudinal environment of disabled children. A number of preliminary qualitative studies were undertaken to ascertain the EFs relevant and important to families of children with cerebral palsy. These were a literature review [18] and a qualitative study [19] followed by focus group work in each country participating in SPARCLE [20]. Parents of children with cerebral palsy were asked which EFs promoted their child's participation and whether the absence of any EFs hindered it. They indicated four main areas – transport, support to the child and family, mobility and independence and attitudes that affected the child's life at home, in school and in the community. The European Child Environment Questionnaire (ECEQ) was developed on the basis of these responses: it elicited information about the availability of a range of EFs in each of these areas.

The objectives of this article are to establish (i) a valid grouping of EFs into domains and (ii) a method of summarising parents' responses that will allow exploration of relationships between child environment and child centred outcomes.

Method

Participants and procedures

The SPARCLE protocol, sampling strategy, participation rates and potential for bias in the sample have been reported in detail [17,21]. Aspects relevant to this study are summarised below.

Children were eligible for the study if born between 31st July 1991 and 1st April 1997 and on registers of children with cerebral that cover eight regions of six European countries (southeast France, southwest France, southwest Ireland, west Sweden, north England, Northern Ireland, east Denmark, and central Italy). There were 1884 such children. Children were randomly sampled following stratification by walking ability [21]. One thousand one-hundred and seventy-four eligible families were sampled and 743 (63%) took part. A further region in northwest Germany recruited 75 children from multiple sources [21]. Thus, the final sample consisted of 818 children. These children were visited at home in 2004/05 by researchers who administered questionnaires to parents and children.

At the home visits, information was obtained about the child's gross motor function and IQ. Gross motor function was assessed using the five categories of the gross motor function classification system (GMFCS) [22]; children were subsequently categorised as having no limitations of walking ability (GMFCS I), some limitations (GMFCS II & III) or unable to walk (GMFCS IV & V). IQ was classified in three categories: >70, 50–70, <50 according to an IQ 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. The distribution of children by region, GMFCS and IQ is shown in Table I.

The ECEQ

The initial ECEQ had 60 items. For most questions, the parent was first asked if the specific EF was needed or not. If it was needed, the parent was then asked if it was available or not. However, for 18

Table I. The 818 children with cerebral palsy. Distribution by region, gross motor function and IQ.

	n	%
Country and region		
Denmark: east	115	14
France:		
southeast	67	8
southwest	77	9
Germany: northwest	75	9
Ireland: southwest	98	12
Italy: central	85	10
Sweden: west	83	10
UK:		
North England	116	14
Northern Ireland	102	12
Gross motor function		
I Walks and climbs stairs, without limitation	257	31
II Walks with limitations	164	20
III Walks with assistive devices	139	17
IV Unable to walk, limited self-mobility	113	14
V Unable to walk, severely limited self-mobility	145	18
IQ		
IQ >70	385	47
IQ: 50–70	186	23
IQ <50	242	30
Information not available	5	1

questions about emotional support, attitudes and essential facilities, it was assumed all children needed the EF, so the possible response categories did not allow the option that the EF was not needed (see Table II).

For each EF, need was scored as 'Not needed' = 0 and 'Needed' = 1. Availability was scored as: 'Not needed' or 'Needed and available' = 0; 'Needed and not available' = 1. The availability of a needed EF was assumed to be equivalent to not needing the EF. Missing responses (2% of all possible responses) were coded as 'Not needed'.

Identifying ECEQ domains

Both authors and a senior research associate independently assigned the EFs to a priori domains of the physical, social support and attitudinal environment at home, school and in the community (see Table II); differences were resolved by discussion. We then excluded EFs if less than 5% of the children – in all categories of impairment of walking ability and IQ – needed the EF and did not have it, since these EFs provided little information about differences between children.

We assumed that the level of availability to the child of needed EFs in each domain could be described by a single underlying factor – often called a 'latent trait' – that was not directly observable but which influenced the responses to the items [23,24]. This factor, which has a different value for each child, was called *child access*. We modelled this factor using the methods described in the Appendix and summarised below.

LISREL models

Some plausible groupings of EFs into domains may not reflect a single underlying factor, so items may have to be dropped from or added to domains in order to produce a more satisfactory model. We therefore used a fast and simple method, LISREL factor models [25,26], to refine the selection of EFs for each a priori domain.

Models of domain structure for need. We postulated that responses regarding children's needs would be more closely correlated than responses about availability and would therefore result in domains with good face validity. Therefore, we first used responses about need to refine the selection of items for the a priori domains. This was possible only for domains in the physical environment and social support in the home as items in other domains such as caring attitudes, assumed they were needed.

Models of domain structure for access. We then refined the structure for all domains using responses regarding the availability of EFs. Next, we checked whether domains within similar areas could be combined: if the correlation between the latent traits describing separate domains was not significantly different from 1, we combined domains [26].

Rasch models

Many statistical methods can be used to model underlying factors, but it is argued that only scales based on Rasch models provide methods that are valid for measurement purposes [27]. Rasch-compatible scales have excellent psychometric properties: for example, they allow us to estimate not only a personal factor, which we call child access, but also the average level of availability of each EF, which we call *environmental feature availability (EF availability)*.

Therefore, our final step was to use the gllamm suite of programs within Stata to generate multilevel Rasch models for each domain, grouping children within regions [28]. In these models, the scale used for child access is such that one unit represents one standard deviation of the variation between children. The goodness-of-fit of models was checked by examination of residuals.

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

Summary of parents' responses

The assignment of items to the a priori domains is shown in Table II. The response rate is shown in Table II and Figure 1.

Of the 49,080 items in ECEQ which should have been completed by the 818 participants, 48,302 (98%) were completed; completion rates varied from 97 to 99% between regions. Questions about physical facilities, social support and attitudes in the home elicited better responses than questions about attitudes at school. Significantly more data were missing for children who were unable to walk than for other children (3% and 1% respectively, $p < 0.0001$).

Table II. Summary of responses to ECEQ items by 818 families.

	Includes items on need	No. (%) of respondents	% responders in each category		
			Not needed	Needed and available	Needed and not available
Physical environment					
Home					
1. Enlarged rooms at home	√	815 *(99.6)*	49	30	21
2. Adapted toilet at home	√	815 *(99.6)*	58	25	16
3. Modified kitchen at home	√	817 *(99.9)*	71	5	23
17. Walking aids	√	*815 (99.6)*	*48*	*49*	*3*
18. Hoists at home	√	817 *(99.9)*	71	13	16
19. Communication aids at home	√	818 *(100)*	75	16	9
45(a). Wheelchair or modified buggy	√	*818 (100)*	*44*	*54*	*2*
School					
47. Ramps at school	√	803 *(98.2)*	49	46	6
48. Adapted toilets at school	√	803 *(98.2)*	49	45	6
49. Lifts at school	√	802 *(98.0)*	66	22	12
50. Communication aids at school	√	798 *(97.6)*	63	32	6
Community					
4. Ramps in public places	√	816 *(99.8)*	45	28	27
5. Adapted toilets in public places	√	813 *(99.4)*	55	22	23
6. Lifts in public places	√	815 *(99.6)*	33	50	17
7. Escalators in public places	√	815 *(99.6)*	62	24	14
8. Suitable doorways in public places	√	817 *(99.9)*	44	36	20
9. Room in public places to move around	√	816 *(99.8)*	42	34	24
10. Smooth pavements in town or village centre	√	815 *(99.6)*	25	36	39
Transport					
11. Adequate vehicle	√	818 *(100)*	26	59	15
12. Accessible car parking	√	816 *(99.8)*	36	43	21
13. Adequate bus service	√	814 *(99.5)*	59	22	19
14. Accessible buses	√	814 *(99.5)*	58	21	20
15. Accessible train services	√	813 *(99.4)*	64	17	19
16. Accessible taxis	√	816 *(99.8)*	53	37	10
Social support					
Home					
20. Receive grants for equipment	√	816 *(99.8)*	34	59	7
21. Receive grants for home modifications	√	805 *(98.4)*	53	23	23
22. Receive grants for holidays	√	814 *(99.5)*	43	21	36
23. Information about financial benefits	√	815 *(99.6)*	11	40	49
25. Emotional support from family members living in home		*815 (99.6)*	-	*99*	*1*
26. Emotional support from wider family/friends		811 *(99.1)*	-	90	10
27. Physical help from family members living in home	√	*814 (99.5)*	*15*	*83*	*2*
28. Physical help from wider family/friends	√	813 *(99.4)*	23	57	20
36. Helper or assistant at home	√	817 *(99.9)*	62	18	20
37. Family look after child for a few hours	√	817 *(99.9)*	30	42	27
School					
30 Teachers/doctors listen to your views		811 *(99.1)*	-	90	10
46(a) Child has school placement s/he needs		798 *(97.6)*	-	91	9
51. Special staff help child in school	√	805 *(98.4)*	16	79	5
57. Child receives physical help from teachers/therapists	√	*801 (97.9)*	*17*	*80*	*3*
60. Teachers have understanding of medical condition		788 *(96.3)*	-	81	19
Community					
24. Suitable leisure facilities		781 *(95.5)*	-	54	46
29. Child receives physical help from people in public places	√	812 *(99.3)*	39	35	25
32. Specialised therapy services	√	815 *(99.6)*	6	88	7
33. Health service staff co-ordinate work well		803 *(98.2)*	-	73	27
34. Social services co-ordinate work well	√	799 *(97.7)*	58	24	18
35. Child looked after elsewhere for few days	√	816 *(99.8)*	61	20	19
38. Parent support groups in area	√	810 *(99.0)*	53	16	31
39. Counselling available	√	805 *(98.4)*	33	34	33
42. People in public places have positive attitude towards child		803 *(98.2)*	-	77	23

(*continued*)

Table II. (*Continued*).

	Includes items on need	No. (%) of respondents	% responders in each category: Not needed	Needed and available	Needed and not available
Attitudes					
Home					
31. Child allowed extra time at home	√	813 *(99.4)*	19	75	6
40. Family members living in home have positive attitude towards child		*812 (99.3)*	-	*99*	*1*
41. Wider family and friends have positive attitude towards child		810 *(99)*	-	95	5
43. Child encouraged to reach potential by family members living in home		*811 (99.1)*	-	*98*	*2*
44. Child encouraged to reach potential from wider family/friends		809 *(98.9)*	-	85	15
School					
52. Child allowed extra time at school	√	773 *(94.5)*	16	72	13
53. Child encouraged to reach potential from teachers/therapists		794 *(97.1)*	-	93	7
54. Child encouraged to reach potential from classmates		727 *(88.9)*	-	77	23
55. Child receives emotional support from teachers/therapists		774 *(94.6)*	-	92	8
56. Child receives emotional support from classmates		724 *(88.5)*	-	79	21
58. Teachers/therapists have positive attitude towards child		*794 (97.1)*	-	*96*	*4*
59. Classmates have positive attitude towards child		758 *(92.7)*	-	92	8

Items are grouped by a priori domains. Items in italics were excluded from models as less than 5% of children, in all categories of walking ability, needed the item and did not have access to it.

Children's environmental needs (Table II and Figure 1)

As regards the physical environment, only a quarter of families said they needed communication aids at home or a modified kitchen, whereas three quarters said they needed an adequate vehicle and smooth pavements. Just over half the children needed wheelchairs and wide doorways. For children without any limitation to walking, the median proportion who needed items in the physical domains was 6% (inter-quartile range: 3–11%), which suggests there is little value in assessing availability of these EFs for these children.

As regards social support, just under 40% of families needed assistance at home or someone outside the family to look after the child for a few days, but nearly all needed specialised therapy services and information about financial help. Over 80% of children needed extra time at home and school.

Availability of needed EFs (Table II and Figure 1)

In the physical environment, few families who needed modified kitchens had them, whereas nearly all children who needed a wheelchair or walking aids had them.

As regards social support, only one-third of families who needed parent support groups and grants for holidays had access to them, but nearly all who needed physical help from close family, teachers or therapists received such help.

Over 96% of families reported that family members living at home gave the child emotional support, had a positive attitude towards the child and encouraged the child to reach his or her potential, and that teachers and therapists had a positive attitude towards the child.

Most children had access to most EFs they needed: the proportion of children without access to a needed EF varied between 1 and 49%, with a median of 16% (inter-quartile range: 7–23%). Even in children unable to walk, the median proportion without access to a needed EF was 25% (inter-quartile range: 6–35%).

Identifying ECEQ domains

The refinement of the a priori domains by dropping items or transferring them between domains is summarised in Table III. Seven items were dropped as less than 5% of children needed the item but did not have access to it (see step 1 of Table III).

LISREL factor models of the domain structure for the physical environment and social support in the home, based on the child's need, led to the refinements summarised in step 2 of Table III. Item 7 (escalators) was dropped from the Physical – community domain. Item 11 (adequate vehicle) and item 12 (car parking) were moved from Transport to Physical – community in order to improve the model fit. The remaining domains – Physical – home, Physical – school and Social support – home – were retained unchanged: although the models were not a

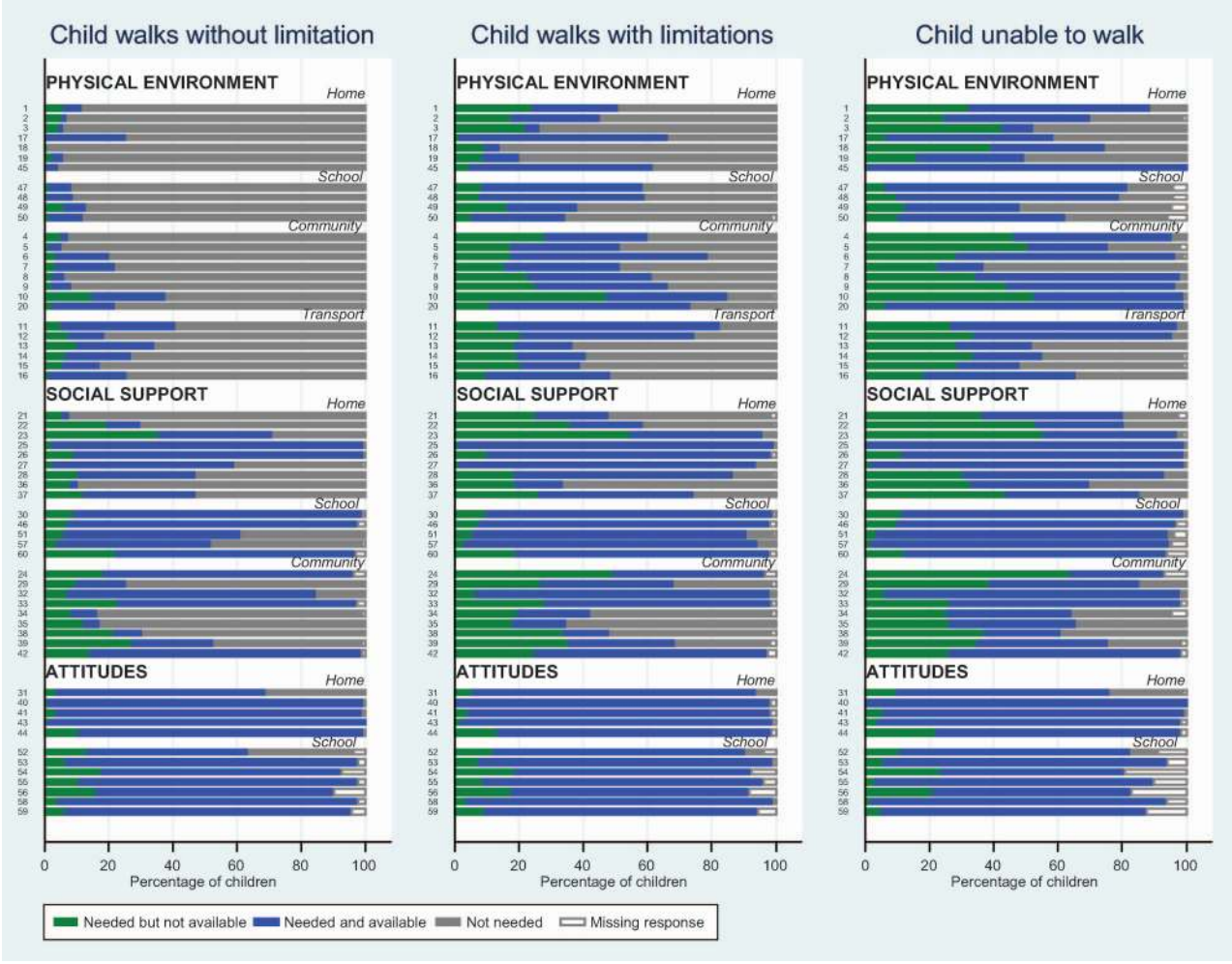

Figure 1. Responses to each item by walking ability. Items are grouped by initial domains.

good fit, removal of poorly fitting items did not substantially improve the fit.

Models of the domain structure for all aspects of the environment, based on responses about availability of EFs led to further refinements, summarised in step 3 of Table III. The models for Physical – school and Transport were a good fit; the models for Physical – community and Attitudes – home were a satisfactory fit; the model for Physical – home was not a satisfactory fit but we were unable to improve the fit by removing items. The model for Social support – home was not a satisfactory fit; the fit was improved but remained unsatisfactory, by moving items 26, 28 and 37 to Attitudes – home, which was relabelled as Attitudes – family and friends. One item (item 32: specialised therapy services) was dropped from Social support – community as it was only weakly correlated with the other items: nevertheless the fit of this domain remained unsatisfactory. The initial model for Attitudes – school (items 52–56, 59) did not have a satisfactory fit, so it was restricted to: Attitudes – classmates (items 54, 56, 59) which had a satisfactory fit. The remaining items (items 52, 53, 55) were combined with Social support – school: the resulting domain was labelled as Attitudes – teachers/therapists and had a satisfactory fit.

We then generated multilevel Rasch models for each domain, using the assignment of items to domains indicated by the LISREL models. Table IV shows the estimated *EF availability* for each item retained in the models; EFs are ordered from the most available to the least available; 95%CIs that overlap indicate items that have similar levels of availability. In domains with fewer than five items (Physical – school, Transport, Attitudes – classmates), 95% CI for all items overlapped, indicating a lack of precision in estimating the underlying latent trait.

Figure 2 shows the distributions of the scores for *child access* in each domain, relative to the *EF availability*, which is shown by the red vertical lines. Children with scores to the left of a line have less than a 50% chance of having access to that EF; conversely, children with scores to the right of the

Table III. Summary of refinement of domain structure.

Item	Domain	Items included in domain	Model fit				Reason for removal of items
			χ^2	d.f.	p	RMSEA	
Step 1: Exclusion of items from a priori domains							
Items dropped:							
45 Wheelchair	*Physical – home*						Less than 5% of children needed the item but did not have access to it
25 Emotional support from family living at home	*Social support - home*						
27 Physical help from family members living in home	*Social support - home*						
57 Physical help from teachers/therapists	*Social support - school*						
40 Family members living in home have positive attitude towards child	*Attitudes - home*						
43 Child encouraged to reach potential by family members living in home	*Attitudes - home*						
58 Teachers/therapists have positive attitude to child	*Attitudes - school*						
Step 2: LISREL factor models of domain structure for need ***(only for physical environment and social support in the home)***							
Items included in initial models:							
	Physical - home	1, 2, 3, 17, 18, 19	58.71	19	< 0.00001	0.083	
	Physical - school	47, 48, 49, 50	23.85	2	0.00001	0.116	
	Social support - home	20, 21, 22, 23, 26, 28, 36, 37	97.07	14	<0.00001	0.086	
	Transport	11, 12, 13, 14, 15, 16	164.44	9	<0.00001	0.146	
	Physical - community	4, 5, 6, 7, 8, 9, 10	129.08	14	<0.00001	0.101	
Item dropped:							
7 Escalators in public places	*Physical - community*	4, 5, 6, 8, 9, 10	21.70	9	0.01	0.042	Removal improved the fit
Items transferred between domains:							
11 Adequate vehicle 12 Adequate car parking	From *Transport* to *Physical - community*						Removal improved the fit of the *Transport* domain without degrading the fit of the *Physical - community* domain
Modified models:							
	Transport	13, 14, 15, 16	14.50	2	0.0009	0.087	
	Physical - community	4, 5, 6, 8, 9, 10, 11, 12	45.80	20	0.0023	0.037	

(*continued*)

Table III. (*Continued*).

Item	Domain	Items included in domain	Model fit				Reason for removal of items
			χ^2	d.f.	*p*	RMSEA	
Step 3: LISREL factor models of domain structure for access							
Initial models:							
	Physical – home	1, 2, 3, 17, 18, 19	39.14	9	0.00001	0.064	
	Physical - school	47, 48, 49, 50	3.72	2	0.16	0.032	
	Physical - community	4, 5, 6, 8, 9, 10, 11, 12	35.60	20	0.02	0.031	
	Transport	13, 14, 15, 16	1.93	2	0.38	<0.001	
	Social support - home	20, 21, 22, 23, 26, 28, 36, 37	125.05	20	<0.00001	0.080	
	Social support - school	30, 46, 51, 60	6.33	2	0.04	0.051	
	Social support – community	24, 29, 32, 33, 34, 35, 38, 39, 42	134.24	27	<0.00001	0.070	
	Attitudes - home	31, 41, 44	0.00	0	1.00	0.000	
	Attitudes – school	52, 53, 54, 55, 56, 59	94.10	9	<0.00001	0.108	
Item dropped:							
32 Specialised therapy services	*Social support - community*						Item had very low factor loading (0.19)
Items transferred between domains:							
26 Emotional support from wider family/friends 28 Physical help from wider family/friends 37 Family look after child for a few hours	From *Social support - home* to *Attitudes - home*, relabelled as *attitudes - family and friends*						Removal improved the fit of the *Social support - home* domain without degrading the fit of the *Attitudes - home* domain
52 Child allowed extra time at school 53 Child encouraged to reach potential from teachers/therapists 55 Child receives emotional support from teachers/therapists	From *Attitudes - school* to *Social support - school*, relabelled as *Attitudes - teachers/therapists*. Remaining items were relabelled as *Attitudes -classmates*						The fit of items in the new domains (*Attitudes - teachers/therapists* and *Attitudes - classmates*) was better than that in the previous domains (*Attitudes - school* and *Social support - school*)
Modified models:							
	Social support - community	24, 29, 33, 34, 35, 38, 39, 42	113.88	20	<0.00001	0.076	
	Social support – home	20, 21, 22, 23, 36	18.97	5	0.0019	0.058	
	Attitudes - family and friends	26, 28, 31, 37, 41, 44	16.03	9	0.07	0.031	
	Attitudes - teachers/therapists	30, 46, 51, 52, 53, 55, 60	24.36	14	0.04	0.030	
	Attitudes - classmates	54, 55, 56	0.00	0	1.00	0.000	

Table IV. Estimated mean EF availability (95%CI) for each ECEQ item.

	Availability	
	Mean	(95%CI)
Physical environment		
Home		
17 Walking aids	4.95	(4.34–5.57)
19 Communication aids at home	3.43	(2.95–3.92)
2 Adapted toilet at home	2.55	(2.10–2.99)
18 Hoists at home	2.52	(2.08–2.97)
1 Enlarged rooms at home	2.06	(1.63–2.50)
3 Modified kitchen at home	1.87	(1.44–2.30)
School		
47 Ramps at school	3.90	(3.23–4.57)
50 Communication aids at school	3.87	(3.20–4.54)
48 Adapted toilets at school	3.76	(3.10–4.42)
49 Lifts at school	2.82	(2.22–3.42)
Community		
11 Adequate vehicle	2.52	(2.15–2.89)
6 Lifts in public places	2.37	(2.01–2.74)
8 Suitable doorways in public places	2.04	(1.69–2.40)
12 Accessible car parking	1.98	(1.62–2.33)
5 Adapted toilets in public places	1.81	(1.46–2.16)
9 Room in public places to move around	1.72	(1.37–2.06)
4 Ramps in public places	1.50	(1.16–1.84)
10 Smooth pavements in town or village centre	0.67	(0.34–1.00)
Transport		
16 Accessible taxis	3.83	(3.07–4.58)
15 Accessible train services	2.65	(1.93–3.36)
13 Adequate bus service	2.59	(1.88–3.30)
14 Accessible buses	2.50	(1.79–3.21)
Social support		
Home		
20 Receive grants for equipment	3.19	(2.79–3.59)
36 Helper or assistant at home	1.74	(1.41–2.06)
21 Receive grants for home modifications	1.54	(1.22–1.86)
22 Receive grants for holidays	0.70	(0.40–1.00)
23 Information about financial benefits	0.01	(−0.29–0.31)
Community		
34 Social services co-ordinate work well	1.83	(1.49–2.17)
35 Child looked after elsewhere for few days	1.75	(1.41–2.09)
42 People in public places have positive attitude towards child	1.52	(1.18–1.85)
29 Child receives physical help from people in public places	1.31	(0.98–1.64)
33 Health service staff co-ordinate work well	1.26	(0.93–1.59)
38 Parent support groups in area	0.94	(0.62–1.27)
39 Counselling available	0.85	(0.52–1.17)
24 Suitable leisure facilities	0.21	(−0.11–0.53)
Attitudes		
Family and friends		
41 Wider family and friends have positive attitude towards child	4.15	(3.64–4.67)
31 Child allowed extra time at home	3.71	(3.24–4.19)
26 Emotional support from wider family/friends	3.03	(2.60–3.46)
44 Child encouraged to reach potential from wider family/friends	2.44	(2.04–2.84)
28 Physical help from wider family/friends	2.01	(1.62–2.39)
37 Family look after child for a few hours	1.40	(1.03–1.76)
Teachers and therapists		
51 Special staff help child in school	4.29	(3.70–4.88)
53 Child encouraged to reach potential from teachers/therapists	3.95	(3.38–4.51)
55 Child receives emotional support from teachers/therapists	3.75	(3.20–4.31)
46(a) Child has school placement s/he needs	3.64	(3.09–4.19)
30 Teachers/doctors listen to your views	3.32	(2.79–3.85)
52 Child allowed extra time at school	3.07	(2.55–3.59)
60 Teachers have understanding of medical condition	2.38	(1.88–2.87)

(*continued*)

Table IV. (*Continued*).

	Availability	
	Mean	(95%CI)
Classmates		
59 Classmates have positive attitude towards child	5.36	(4.32–6.39)
56 Child receives emotional support from classmates	3.36	(2.45–4.28)
54 Child encouraged to reach potential from classmates	3.12	(2.22–4.03)

Items are grouped by the final domains and ordered from the most widely available to the least available. Higher values indicate better availability. The scale is such that one unit represents one standard deviation of the variation in availability.

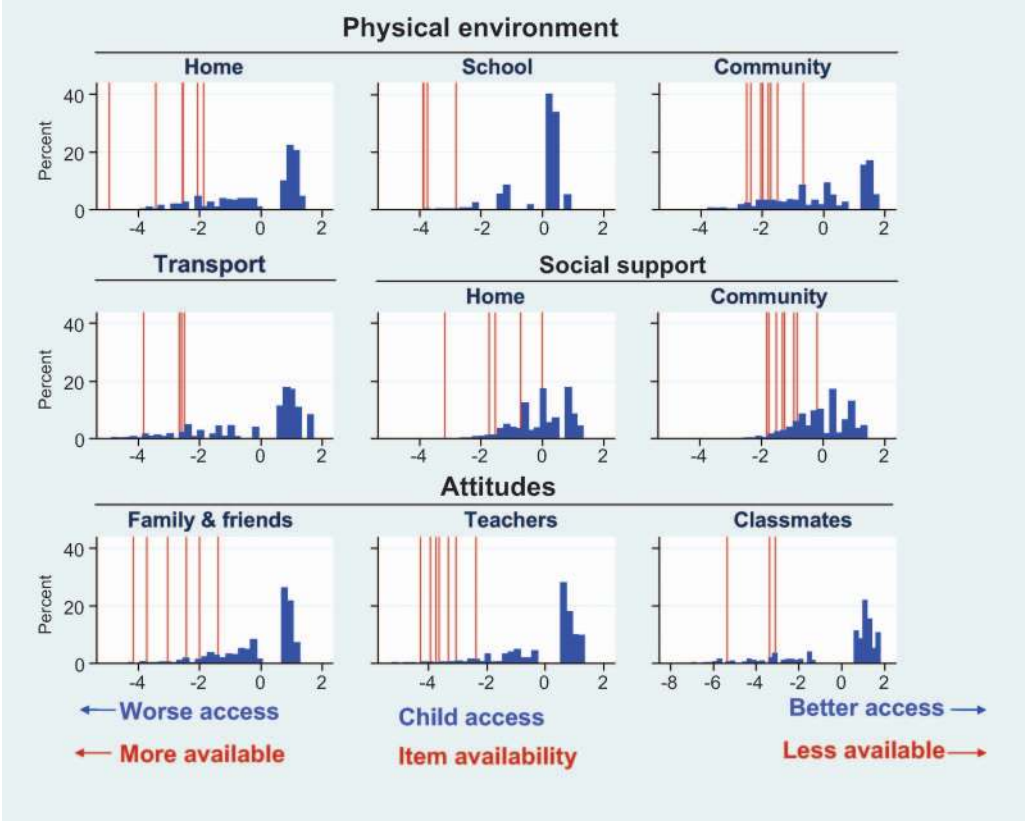

Figure 2. Distribution of latent trait in each domain. Items are grouped by final domains. The scale is such that one unit represents one standard deviation of the variation between children. Vertical red lines show the estimated availability of each environmental feature.

line have more than a 50% chance of having access to it. Hence Figure 2 indicates how well the items are targeted to the study population. It confirms what was apparent from the raw responses: most children had access to most EFs they needed. Even among children who were unable to walk, the pattern was similar, although less marked.

Goodness-of-fit

For all domains, principal components analysis showed that residuals were correlated to the extent that their first principal component was significantly greater than would be expected by chance ($p < 0.01$) [29,30]. This suggests that, contrary to the assumptions underlying the model, more than one underlying factor influenced each domain.

Plots of the distribution of residuals by region showed that only one domain (Attitudes – teachers and therapists) generally had low residuals for all items in all regions. The Physical – school domain tended to have low residuals for all items in all regions except central Italy. The Physical – home, Social support – home, Physical – community, Social support – community domains showed large residuals for many items in most regions. Other domains showed large residuals for specific items in all regions except north England, Northern Ireland and east Denmark.

Plots of standardised residuals in 10 groups ordered by the level of the latent trait showed a trend across groups for many items: for children with low access as estimated by the underlying latent trait, access to a specific item was predicted to be higher than observed and conversely for children with high access. Three domains (Physical – school, Transport, Attitudes – classmates) showed little evidence of such an item-trait interaction; but several items (items 2, 20, 21, 26, 29) in other domains did so, indicating that they discriminated between children more sharply than other items in the same domain [31].

Discussion

Summary of main findings

The ECEQ was relevant and acceptable to parents of disabled children: the proportion of items to which they did not respond was very low (2%). Our analysis identified nine domains with face validity, though other groupings of items into domains may also be valid. ECEQ items in the physical environment were generally not needed by children who had no limitation of walking ability, so domains describing the physical environment could be omitted when the questionnaire is administered to such children.

We identified nine domains: the 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. Each domain was described by between three and eight items. Of the 60 items included on the basis of focus groups with parents of children with cerebral palsy, seven items (see Table III) were not included in any domain, because less than 5% of children needed them but did not have access to them. Two further items (see Table III) were excluded because they were only weakly correlated with other items in the domains describing similar aspects of the environment.

Strengths and weaknesses

The face validity of ECEQ is strong as its items were derived from a literature review, followed by in depth interviews and focus group work with parents of children with cerebral palsy in the participating European regions. We did not attempt to obtain an objective account of the environment around a child as this would have required detailed, time-consuming and expensive research of local facilities for every child. Rather, we asked parents whether features of the environment which they thought they needed were available to their child. It is possible that some parents were unaware of some features of the environment that were available but, from the point of view of that child and family, such EFs were in practice unavailable.

Participants in SPARCLE were representative of children with cerebral palsy in the selected regions [21]. However, our findings represent the average for all regions and individual regions will almost certainly show variability about this average, as discussed in the companion paper in this issue. The proportion of missing data was very low, both overall (2%) and among children who were unable to walk (3%). The main uncertainty is around attitudes of classmates to children who were unable to walk.

Although we used Rasch models, which have excellent psychometric properties, and we allowed for variation between regions, our data did not fit the models well enough to satisfy the stringent criteria required of a measurement instrument. Nevertheless, these models are useful for our purposes, since our primary motivation for assessing the environment was to understand the relationship between the environment and outcomes such as participation and quality of life among a large sample of children with cerebral palsy, rather than to provide a measure of the environment of an individual child [32]. The Rasch model that we used can readily be extended to a latent regression Rasch model (see Equation (2) in appendix) that regresses child access on covariates such as the child's impairment or socio-demographic characteristics [32].

Our statistical models assumed that the responses to the items in each domain were correlated because they were influenced by an underlying factor such as regional policy; in this situation, the items are called *effect indicators* [24]. Such an approach has underpinned the construction of other widely used indices summarising the environment [33]. Where responses to items define a construct rather than vice versa, they are called *causal indicators*. In this situation, the responses to the items may not be correlated [34,35]. Items in the transport and the social support domains did not fit the model well. This may be because the items in these domains function as *causal indicators* [24]. For example, a family which has a suitable vehicle for their child may not need accessible buses, trains and taxis. Alternatively, lack of fit may reflect different patterns of correlations in different groups. For example, items in the social support domains may have different correlations in different regions.

The questionnaire did not target the population as much as it might have done; most children had access to most EFs they needed whereas, ideally, the proportions of children without access to EFs should

cluster around 50%, where measurement error is lowest [36].

ECEQ generates scores that reflect parents' perceptions of the unmet environmental needs of their child. These scores are therefore influenced by the child's type and level of impairment. If the effects of environment alone are to be detected in any analysis relating outcomes – such as participation and quality of life – to ECEQ scores, it is therefore essential to control statistically for impairment. Ideally, instruments designed to measure the environment of disabled children for epidemiological purposes would not be influenced by individual impairments. However, this would require capture of information on the availability of features of the environment even if they were not needed by a child, which might in practice be difficult to achieve.

Comparison with other instruments

ECEQ covers all aspects of a child's life whereas some other instruments [11,12] are restricted to assessment of the school environment. The School Setting Interview [12] demonstrated good sensitivity, specificity and inter-rater reliability of items, but did not attempt to combine individual items into summary scores. This was largely because it was developed to provide occupational therapists with practical guidance about adjusting the school environment to meet the needs of each individual student. The task supports domains of the School Function Assessment [11] summarise the practical help with physical and cognitive tasks given to children in school; Rasch models are used to combine items into summary scores.

The CASE instrument, like ECEQ, covers the physical, social and attitudinal environment, but it contains only 15 items, in contrast to the 51 items that we retained in ECEQ. CASE scores items as posing no problem, a little problem or a big problem and, like ECEQ, also allows a ''not applicable'' response. Hence CASE, like ECEQ, generates scores that are influenced by the child's type and level of impairments. Factor and Rasch analysis were used in attempts to model CASE [14]: but it appeared not to function as a uni-dimensional scale, which is not surprising as it covered all aspects of the environment. It may be more realistic to use separate domains for different aspects of the environment, as in ECEQ.

ECEQ has been used by other investigators [37] who identified domains by conducting a categorical principal components analysis, a method which is widely used in social sciences in analyses of complex categorical data. They analysed response categories of: not needed, needed and available and helps a little, needed and available and helps a lot, needed and not available and restricts a little, needed and not available and restricts a lot. Hence their environmental score conflated the concepts of need, availability of EFs and outcomes (helps/restricts a little/a lot).

Although we identified areas of ECEQ that could be improved, the current version provides useful insight into the relationship between the child's environment and child-centred outcomes. The development of an instrument that is satisfactory in all respects is usually a long, iterative process [38,39].

Recommendations about assessment of environment of disabled children

In further development of the ECEQ, it should be possible to omit EFs (see step 1 in Table III), to which almost all children have access, as these discriminate only between children who have very poor access. Ideally, the questionnaire should be supplemented by more items about features of the environment to which disabled children are likely to have low access, so that the questionnaire targets the population better. Items about attitudes need to be more discriminatory. Domains with only three or four items – Physical – school, Transport, Attitudes – classmates – should be supplemented by more items so that the underlying latent trait can be estimated more precisely. Items that are poorly correlated with other items in domains to which they could plausibly be assigned (e.g. items 7 and 32 – see step 2 of Table III) should be reconsidered: more precise wording might elicit responses that are more consistent with those to similar items.

Conclusions

Much still needs to be learned about how to capture and model the environment of disabled children [40]. There are practical problems in obtaining valid information about the availability of features of the environment that parents judge to be not needed by their child.

Nevertheless, we have developed an instrument with a stronger psychometric underpinning than previous instruments. We have refined and evaluated a domain structure that allows ECEQ to be used in statistical modelling relating children's outcomes, such as participation and quality of life, to their environment. Although we cannot yet recommend a scoring system that can be generalised to other populations of children, our paper exemplifies a methodology that could use in other populations to

fit an underlying factor to item responses in each domain and recommends that analyses are stratified by the child's level of impairment.

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Appendix. Factor models of need and access

Lisrel models

Within each domain, we used factor models of the form:

$$\mathbf{y} = \Lambda_{\mathbf{y}}\eta + \varepsilon$$

where $\mathbf{y}$ is a vector of observed responses to items concerning either need or access, $\Lambda_{\mathbf{y}}$ is a vector of factor loadings, η is a latent trait (or variable) and ε is a vector of measurement errors in $\mathbf{y}$; ε and η are uncorrelated [25]. The observed responses were binary (i.e. either needed/not needed; needed but not available/other), whereas the unobserved (latent) variables were assumed to be continuous and multivariate normal. The factor loadings, $\Lambda_{\mathbf{y}}$, were estimated using weighted least squares [25].

Starting from a tentative initial model, we assessed whether the model should be modified – for example, by removing questions – and tested the revised model. This process was repeated until the model was a satisfactory fit or could not be further improved.

The validity of the model was assessed by: the direction and magnitude of the factor loading (indicating the correlation between the item and the latent variable); the R^2 statistic that summarised what percentage of the variation in the observed item was explained by the latent variable [41]. The goodness-of-fit was assessed by chi-square and the root mean square error of approximation. If any of these quantities indicated a poor fit to the data, the residuals, modification indices and expected change were examined to locate the source of misspecification and suggest how the model could be modified.

Gllamm models

We then used the gllamm suite of programs within Stata to generate multilevel Rasch models that allowed for the grouping of children within regions. Rasch models relate the probability P_{ni} that child n needs but does not have access to item i to *child access*, Θ_n (which is an unobserved latent trait) and to *environmental feature availability*, B_i:

$$logit \quad (P_{ni}|\Theta_n) = \Theta_n - B_i \tag{1}$$

This can readily be extended to a latent regression Rasch model [32] if it is assumed that:

$$\Theta_n = \sum_{j=1}^{\mathcal{J}} \vartheta_j Z_{nj} + \varepsilon_n \tag{2}$$

where Z_{nj} is the value of covariate j ($j=1, \ldots, \mathcal{J}$) for child n; ϑ_j are regression coefficients to be estimated; and $\varepsilon_n \sim N(0, \sigma_\varepsilon^2)$ is a random intercept.

Environmental feature availability, B_i was treated as a fixed parameter and the parameters were estimated using marginal maximum likelihood [28]. From these models, we used empirical Bayes prediction to estimate scores that quantified each child's access within each domain. Although methods of estimating the parameters in simple Rasch models allow estimation of these person parameters from the sum score (the total number of positive responses), this was not possible for a multilevel model [23].

Assessment of goodness-of-fit

We performed a principal components analysis of the residuals for each item: if the residuals were

correlated such that their first principal component was significant ($p < 0.01$) [29,30], this suggested more than one underlying latent trait in the domain [42].

Item-trait interaction test of fit

We examined whether items behaved in the same way at different levels of the latent trait [31]. We divided the range of the underlying latent trait into 10 adjacent groups with approximately equal numbers of children in each group. Within each group, we summed the difference between the observed and expected responses, standardised by dividing by the expected standard deviation of the responses, and checked how these differences varied across groups. If the item behaved in the same way for all levels of the latent trait, these standardised differences would show no systematic pattern.

Differential item functioning

We plotted the distribution of residuals by region, in order to check whether the items worked in the same way for children in different regions [27].