

Association Between Participation in Life Situations of Children With Cerebral Palsy and Their Physical, Social, and Attitudinal Environment: A Cross-Sectional Multicenter European Study

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ABSTRACT. Colver A, Thyen U, Arnaud C, Beckung E, Fauconnier J, Marcelli M, McManus V, Michelsen SI, Parkes J, Parkinson K, Dickinson HO. Association between participation in life situations of children with cerebral palsy and their physical, social, and attitudinal environment: a cross-sectional multicenter European study. *Arch Phys Med Rehabil* 2012;93:2154-64.

Objective: To evaluate how participation of children with cerebral palsy (CP) varied with their environment.

Design: Home visits to children. Administration of Assessment of Life Habits and European Child Environment Questionnaires. Structural equation modeling of putative associations between specific domains of participation and environment, while allowing for severity of child's impairments and pain.

Setting: European regions with population-based registries of children with CP.

Participants: Children (n=1174) aged 8 to 12 years were randomly selected from 8 population-based registries of children with CP in 6 European countries. Of these, 743 (63%) agreed to participate; 1 further region recruited 75 children from multiple sources. Thus, there were 818 children in the study.

Interventions: Not applicable.

Main Outcome Measure: Participation in life situations.

Results: For the hypothesized associations, the models confirmed that higher participation was associated with better availability of environmental items. Higher participation in daily activities—mealtimes, health hygiene, personal care, and

home life—was significantly associated with a better physical environment at home ($P<.01$). Mobility was associated with transport and physical environment in the community. Participation in social roles (responsibilities, relationships, recreation) was associated with attitudes of classmates and social support at home. School participation was associated with attitudes of teachers and therapists. Environment explained between 14% and 52% of the variation in participation.

Conclusions: The findings confirmed the social model of disability. The physical, social, and attitudinal environment of disabled children influences their participation in everyday activities and social roles.

Key Words: Cerebral palsy; Child; Environment; Models, statistical; Rehabilitation; Social participation.

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PARTICIPATION IS an important outcome for all children, but little is known about participation of disabled children.

The *International Classification of Functioning, Disability and Health for Children and Youth* (ICF-CY)^{1(p9,15)} defines participation as “involvement in life situations,” impairments as “problems in body structure or function,” and contextual factors as “external environmental factors in the social, physical and attitudinal environment or personal factors such as gender, age, personality.” The ICF-CY considers disability to result from an interaction between a person's impairment and their context. Thus, participation restriction is presumed to result at least in part from a failure of the environment to adjust to the individual—a view consistent with the social model of disability.²

Two United Nations (UN) conventions emphasize the importance of participation: Article 23 of the UN Convention on the

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List of Abbreviations

CFI	comparative fit index
CHIEF	Craig Hospital Inventory of Environmental Factors
CP	cerebral palsy
ECEQ	European Child Environment Questionnaire
ICF-CY	<i>International Classification of Functioning, Disability and Health for Children and Youth</i>
RMSEA	root mean square error of approximation
SPARCLE	Study of PARTICipation of Children with cerebral palsy Living in Europe
UN	United Nations

Rights of the Child³ states that “a mentally or physically disabled child 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 9 of the UN Convention on the Rights of Persons with Disabilities⁴ asserts the obligation of states “to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, transportation, information and communications.”

If resources are to be directed to implementing these UN resolutions, governments need evidence from large quantitative studies of children about whether environmental adjustments do promote participation of disabled children. There is little such evidence, a recent systematic review⁵ finding only 4 small quantitative studies on the relationship of children’s participation to their environment.

The Study of PARTICipation of Children with cerebral palsy Living in Europe (SPARCLE)⁶ examines how participation of children with cerebral palsy (CP) relates to their environment in 9 European regions. Children with CP were studied, because CP is the most common cause of significant motor impairment in childhood (occurring in 1 in 500 births), and such children often have other impairments of learning, communication, and epilepsy in addition to their motor impairments and therefore are exemplars of the wider population of disabled children. In the SPARCLE study, we found that European countries vary in the environmental adaptations they make for disabled children^{7,8} and that, for children with CP, both participation⁹ and environmental access¹⁰ vary by region. By environmental access we are referring to the social, attitudinal, and physical environment in the home, school, and community such as adapted toilet at home, encouragement by teachers to reach potential, and well-integrated health care in the community. Furthermore, regions where children experienced above average participation generally had better environmental access. However, such relationships must be confirmed at an individual level in order to support the argument that environmental adjustment promotes participation.¹¹ The objective of this article is to evaluate the principal hypothesis of SPARCLE, which states that for children with similar severity of impairment, participation varies depending on their environment.

METHODS

Participants and Procedures

The SPARCLE protocol, sampling strategy, response rates, and potential for sample bias have been reported in detail^{6,12} and are summarized below.

Children were eligible if born between July 31, 1991 and April 1, 1997 and on registries of children with CP that cover 8 regions of 6 European countries (southeast France, southwest France, southwest Ireland, west Sweden, north England, Northern Ireland, east Denmark, and central Italy). The 1884 eligible children were randomly sampled after stratification by walking ability, as recorded when the children were originally recruited to the registries: no functional consequences but walking may not be normal; walking restricted but unaided; walking limited and needs aids; unable to walk.¹³ There were 1,174 families included in the target sample, and 743 (63%) took part. A further region in northwest Germany recruited 75 children from multiple sources.¹² Thus, there were 818 children in total who were visited at home in 2004 through 2005 by researchers who administered questionnaires to parents to assess their child’s environment, participation in everyday activities, and social roles, pain, impairments, and sociodemographic characteristics.

Impairment and Pain

Parents and researchers completed questionnaires together about the child’s impairments. These impairments and their se-

verity (gross motor function,¹⁴ fine motor skills,¹⁵ intellectual ability, seizures, feeding, communication) are shown in [table 1](#). Intelligence quotient was classified in 3 categories: >70, 50 to 70, and <50 according to the intelligence quotient assessment if one was available in the last year and, if not, by a cognitive estimation completed by asking parents about their child’s understanding, learning, and friendships. Frequency and severity of pain in the previous week were recorded using the 2 items from the Child Health Questionnaire,¹⁶ but with the time frame changed from 4 weeks to 1 week to be consistent with that used in other instruments in SPARCLE. The distribution of sociodemographic characteristics, impairment, and pain is summarized in [table 1](#).

Measure of Child Environment

The availability of needed environmental features was assessed using the European Child Environment Questionnaire (ECEQ),¹⁷ which originally included 60 items. The ECEQ asks about environmental features that are important to families of children with CP, and which had been identified by a literature review,¹⁸ qualitative study,¹⁹ and focus group work²⁰ in each country participating in SPARCLE. Factor analysis suggested that 51 items could be combined into 9 domains,¹⁷ which are set out in [table 2](#). For 37 items (marked with * in [table 2](#)), parents were first asked if the item was needed by the child and, if it was, whether the item was available. The remaining 14 items were assumed to be needed by all children. Responses to items were coded as binary variables: needed and not available = 0 and needed and available = 1. If the item was not needed, its availability was imputed using multiple imputation (see Statistical Methods section).

Measure of Child Participation

Participation was assessed using Assessment of Life Habits,²¹ which has been validated in disabled children,²¹ including those with CP.²² It comprises 62 items grouped into 11 domains covering daily activities and social roles. The 9 domains we use in this article are set out in [table 3](#), the other 2 domains being communication and community life. We also omitted 1 question about sexual relationships, because it was inappropriate to this age group. For 15 items that concern nondiscretionary participation regarded as essential to a child’s daily life, the parent is asked if the child achieves it with or without difficulty. For the other 47 items, the parent is asked if the child achieves it and, if yes, whether with or without difficulty. Responses are coded as ordinal variables (performed without difficulty, performed with difficulty, not performed because too difficult, missing if not performed for other reasons).

All items in Assessment of Life Habits also ask whether the child needs assistance to participate. Our analysis ignored the questions about assistance, because we wanted to assess participation without incorporating any influence of environmental factors.⁹

Prior Hypotheses

We hypothesized associations between specific domains of participation and environment, as shown in the first and second columns of [tables 4](#) and [5](#). We hypothesized that children’s physical environment at home influenced their participation in most home-based daily activities; that transport and the physical environment in the community influenced their mobility outside the home; and that specific environmental domains influenced specific social roles.

Statistical Methods

We treated both participation and environment as latent variables. Thus, we assumed that each of the domains of

Table 1: Summary of Distribution of Sociodemographic Characteristics, Impairment, and Pain (N=818)

Child Characteristics	n	%
Country: region		
France: southeast France	67	8
France: southwest France	77	9
Germany: northwest Germany	75	9
Ireland: southwest Ireland	98	12
Sweden: west Sweden	83	10
UK: north England	116	14
UK: Northern Ireland	102	12
Denmark: east Denmark	115	14
Italy: central Italy	85	10
Sex		
Boys	484	59
Girls	334	41
Age (y)		
7	13	2
8	171	21
9	158	19
10	166	20
11	159	19
12	124	15
13	27	3
Impairment		
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
Fine motor skills		
I: without limitation	281	34
II: both hands limited in fine skills	205	25
III: needs help with tasks	131	16
IV: needs help and adapted equipment	91	11
V: needs total human assistance	110	13
Intellectual impairment		
None or mild (IQ>70)	385	47
Moderate (IQ 50–70)	186	23
Severe (IQ<50)	242	30
Information not available	5	1
Seizures		
No seizures in previous year	650	79
Seizures in previous year	167	20
Information not available	1	0
Feeding		
No problems	583	71
Feeds orally with difficulty	176	22
Partial or complete feeding by tube	58	7
Information not available	1	0
Communication		
Normal speech	463	57
Difficulty but uses speech	133	16
Uses nonspeech for formal communication	98	12
No formal communication	123	15
Information not available	1	0
Parental report of child pain in the previous week		
Severity of pain		
None	240	29
Very mild or mild	353	43
Moderate, severe, or very severe	213	26
Information not available	12	1

Table 1 (Cont'd): Summary of Distribution of Sociodemographic Characteristics, Impairment, and Pain (N=818)

Child Characteristics	n	%
Frequency of pain		
None of the time	237	29
Once or twice or a few times	414	51
More often	155	9
Information not available	12	1

Abbreviation: IQ, intelligence quotient.

participation and environment could be summarized by a single factor that could not be observed directly, but which determined the parents' responses to the items.^{23,24} These factors were estimated from the parents' responses to the items in the relevant domain, using structural equation modeling. As with all latent variables, arbitrary constraints were introduced in order to define the scale of the environmental and participation factors: we constrained the loading of the first item of each factor to be equal to 1.

The structural equation models²⁵ related specific domains of participation to specific environmental domains, according to our prior hypotheses, while allowing for impairment and pain. We used multiple imputation²⁵ to impute environmental data that were missing due either to a lack of response or because the feature was not needed. Within each region, missing data for each item were assigned after randomly sampling from a distribution with the observed proportion of available items. Hence, the data for each item—and the latent variables estimated from these data—reflected the availability or nonavailability of environmental items and did not reflect the child's need (or lack of need) for the item. Five imputed datasets were generated. Confidence intervals reflected the uncertainty in each model because of both ordinary sampling variation and imputation of missing data. Statistical analysis was performed using Mplus.^a

The structural equation model for the hypothesized association between the child's physical environment at home and participation in home life is shown in figure 1; models for hypothesized associations between other domains of participation and environment were similar, using the items from the relevant Assessment of Life Habits and ECEQ domains. Our main objective was to estimate the magnitude of the regression coefficient (labeled b in fig 1) relating participation to environment, while adjusting for impairment and pain. Impairment was modeled as a factor expressed through the observed impairments²⁶ gross motor function, fine motor skills, intellectual ability, seizures, feeding, communication, and with a correlation between gross and fine motor skills. Pain was modeled as a factor expressed through the observed frequency and severity of pain. The covariance matrix was analyzed using mean and variance-adjusted weighted least squares with robust SEs and pairwise deletion of missing data. Covariates that were not statistically significant (Wald $P > .05$) were dropped from the model. Model fit was assessed using the root mean square error of approximation (RMSEA) and the Comparative Fit Index (CFI). Models were adjusted until the fit indices were satisfactory, by inspecting modification indices and omitting items (ECEQ or Assessment of Life Habits responses) or adding correlations between items, or between items and factors, as appropriate (see appendix 1).

Where several environmental domains were significant predictors of the same domain of participation, we used a stepwise procedure to assess which environmental domains were independently significant. We selected the most significant domain and built further models that included this domain and each of the

remaining domains in turn; we again selected the most significant additional domain and repeated this procedure until no further domains were significant. To avoid spurious significance consequent to multiple hypothesis testing, we regarded Wald $P < .01$ as statistically significant. The final models excluded children with missing data on impairment and pain.

We report results as standardized regression coefficients (b coefficients), which allow within-study comparison of the effects of different predictors,²³ in particular comparison of the effects of environment and impairment. They estimate the change in participation, in standard deviation units, consequent to a change of 1SD in the independent variable (environment, impairment, or pain).

As an indicator of the variation in participation explained by environment, we noted the percentage increase in the residual variance of participation consequent to removing environment from the model, while constraining the measurement model for participation to remain unchanged. It was not possible to separate the percentage of total variance that was explained by pain and impairment, because we knew from earlier analysis²⁷ that these factors were correlated, unlike environment, which was not expected to be correlated with either explanatory latent variable.

Ethics

Ethics committee approval was obtained in each country. The study was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All parents gave written consent. All children with sufficient cognitive capacity gave written consent or communicated consent if unable to write.

RESULTS

A total of 818 families joined the study. The distribution of the types and levels of the children's impairments and the parents' reports of their child's pain is shown in table 1. Six children (0.7%) had missing data on any type of impairment; 12 (1.5%) had missing data on parent-reported pain. For the ECEQ, the proportion of missing responses ranged from zero for items 11 and 19 to 11% for item 56 (see table 2). The proportion of ECEQ items that were not needed ranged from zero (for items 24, 26, 30, 33, 41, 42, 44, 46, 53–56, 59, 60, which were assumed to be needed by all children) to 75% for item 19 (communication aids at home). For Assessment of Life Habits, the proportion of missing responses ranged from zero for item 2 to 8% for item 52 (see table 3). Responses to Assessment of Life Habits were additionally coded as missing if the child did not perform the task because s/he was not interested or the activity was not relevant to their age; the proportion of such responses varied from zero for item 45 to 50% for item 40.

Daily Activities

More severe impairment was associated with lower participation on all domains considered (see table 4). More pain was significantly associated with lower participation in health hygiene, personal care, and home life. After allowing for impairment and pain, a better physical environment at home was significantly ($P < .01$) associated with higher participation in mealtimes, personal care, and home life; the association with health hygiene was of marginal statistical significance ($P = .011$). Better mobility was associated with both better transport and a better physical environment in the community, but after allowing for the former association, the latter was of marginal statistical significance ($P = .025$). Comparison of regression coefficients indicated that

environment had less impact on these domains of participation than impairment, but more impact than pain. Environment explained between 14% and 30% of the variation in participation. The fit of all models was satisfactory (RMSEA $\leq .05$, CFI $> .95$).

Social Roles

As shown in table 5, most but not all of the hypothesized associations between environment and participation in social roles were statistically significant ($P < .01$). The following hypothesized associations remained significant: between participation in responsibilities and the physical environment at home, attitudes of family and friends, attitudes of classmates, social support at home, social support in the community; between participation in relationships and attitudes of family and friends, attitudes of classmates; between participation at school and attitudes of teachers and therapists; and between participation in recreation and transport, attitudes of family and friends, social support at home, social support in the community. However, some environmental domains that significantly predicted participation when considered individually were not included in our final models, because they were highly correlated with other environmental domains. For example, in the model of participation in responsibilities, the correlations between the physical environment at home, attitudes of family and friends, attitudes of classmates, and social support in the community with social support at home were .81, .26, .23, and .82 respectively; therefore, the former domains were not significant if social support at home was included in the model. In the model of participation in relationships, the correlation between attitudes of family and friends and attitudes of classmates was .42, and therefore the former was not significant if the latter was included in the model. In the model of recreation, the correlations of transport and attitudes of family and friends with social support at home were .59 and .44, respectively, and therefore social support at home was not significant when both transport and attitudes of family and friends were included in the model. Similar but lower correlations resulted in exclusion of social support in the community; however, the correlation between transport and attitudes of family and friends was .22, and therefore both these factors remained in the model. Hence, social support in the home was the strongest independent predictor of participation in responsibilities, attitudes of classmates were the strongest predictor of participation in relationships, attitudes of teachers and therapists were the strongest predictor of participation in school life, and both transport and attitudes of family and friends independently predicted participation in recreation. Pain was removed from the final models because it was not statistically significant and correlations were added as appropriate (see appendix 1). This yielded the final models shown in table 6. Environment explained between 15% and 52% of the variation in participation. The fit of the models for all domains, except that of relationships, was satisfactory (RMSEA $\leq .05$, CFI $> .95$).

DISCUSSION

Summary of Main Findings

Our findings support the principal hypothesis of SPARCLE that, among children with similar severity of impairment, higher participation is associated with the availability of a better environment. More favorable attitudes—of family and friends, of teachers and therapists, and of classmates—were an important component of the environment, being associated with better participation in several aspects of social roles. For participation in daily activities, a more accessible physical environment was associated with better participation.

Child environment, as measured by the ECEQ, accounted for between 14% and 52% of the variation in participation between children.

Table 2: Summary of Distribution of Responses to ECEQ Items (N=818)

ECEQ Domains and Items	No. (%) of Respondents	No. (%) Responders in Each Category		
		Not Needed (coded as missing)	Needed and Not Available (coded as 0)	Needed and Available (coded as 1)
Physical environment				
Home				
1. Enlarged rooms at home*	815 (100)	399 (49)	172 (21)	244 (30)
2. Adapted toilet at home*	815 (100)	476 (58)	132 (16)	207 (25)
3. Modified kitchen at home*	817 (100)	584 (71)	190 (23)	43 (5)
17. Walking aids*	815 (100)	395 (48)	24 (3)	396 (48)
18. Hoists at home*	817 (100)	578 (71)	134 (16)	105 (13)
19. Communication aids at home*	818 (100)	611 (75)	76 (9)	131 (16)
School				
47. Ramps at school*	803 (98)	390 (48)	46 (6)	367 (45)
48. Adapted toilets at school*	803 (98)	394 (48)	51 (6)	358 (44)
49. Lifts at school*	802 (98)	526 (64)	99 (12)	177 (22)
50. Communication aids at school*	798 (98)	499 (61)	47 (6)	252 (31)
Community				
4. Ramps in public places*	816 (100)	366 (45)	220 (27)	230 (28)
5. Adapted toilets in public places*	813 (99)	445 (54)	188 (23)	180 (22)
6. Lifts in public places*	815 (100)	272 (33)	136 (17)	407 (50)
8. Suitable doorways in public places*	817 (100)	359 (44)	165 (20)	293 (36)
9. Room in public places to move around*	816 (100)	341 (42)	197 (24)	278 (34)
10. Smooth pavements in town or village center*	815 (100)	203 (25)	319 (39)	293 (36)
11. Adequate vehicle*	818 (100)	210 (26)	124 (15)	484 (59)
12. Accessible car parking*	816 (100)	293 (36)	171 (21)	352 (43)
Transport				
13. Adequate bus service*	814 (100)	478 (58)	157 (19)	179 (22)
14. Accessible buses*	814 (100)	476 (58)	164 (20)	174 (21)
15. Accessible train services*	813 (99)	523 (64)	153 (19)	137 (17)
16. Accessible taxis*	816 (100)	431 (53)	82 (10)	303 (37)
Social support				
Home				
20. Receive grants for equipment*	816 (100)	280 (34)	56 (7)	480 (59)
21. Receive grants for home modifications*	805 (98)	430 (53)	186 (23)	189 (23)
22. Receive grants for holidays*	814 (100)	348 (43)	296 (36)	170 (21)
23. Information about financial benefits*	815 (100)	90 (11)	400 (49)	325 (40)
36. Helper or assistant at home*	817 (100)	505 (62)	164 (20)	148 (18)
Community				
24. Suitable leisure facilities	781 (95)	0 (0)	362 (44)	419 (51)
29. Child receives physical help from people in public places*	812 (99)	318 (39)	206 (25)	288 (35)
33. Health service staff coordinate work well	803 (98)	0 (0)	213 (26)	590 (72)
34. Social services coordinate work well*	799 (98)	460 (56)	147 (18)	192 (23)
35. Child looked after elsewhere for few days*	816 (100)	495 (61)	155 (19)	166 (20)
38. Parent support groups in area*	810 (99)	426 (52)	255 (31)	129 (16)
39. Counseling available*	805 (98)	264 (32)	269 (33)	272 (33)
42. People in public places have positive attitude toward child	803 (98)	0 (0)	181 (22)	622 (76)
Attitudes				
Family and friends				
26. Emotional support from wider family/friends	811 (99)	0 (0)	85 (10)	726 (89)
28. Physical help from wider family/friends*	813 (99)	187 (23)	162 (20)	464 (57)
31. Child allowed extra time at home*	813 (99)	153 (19)	52 (6)	608 (74)
37. Family/friends look after child for a few hours*	817 (100)	248 (30)	224 (27)	345 (42)
41. Wider family and friends have positive attitude toward child	810 (99)	0 (0)	37 (5)	773 (94)
44. Child encouraged to reach potential from wider family/friends	809 (99)	0 (0)	125 (15)	684 (84)
Teachers and therapists				
30. Teachers/doctors listen to your views	811 (99)	0 (0)	84 (10)	727 (89)
46(a.) Child has school placement s/he needs	798 (98)	0 (0)	68 (8)	730 (89)
51. Special staff help child in school*	805 (98)	127 (16)	43 (5)	635 (78)
52. Child allowed extra time at school*	773 (94)	120 (15)	98 (12)	555 (68)
53. Child encouraged to reach potential from teachers/therapists	794 (97)	0 (0)	55 (7)	739 (90)
55. Child receives emotional support from teachers/therapists	774 (95)	0 (0)	63 (8)	711 (87)
60. Teachers have understanding of medical condition	788 (96)	0 (0)	147 (18)	641 (78)

Table 2 (Cont'd): Summary of Distribution of Responses to ECEQ Items (N=818)

ECEQ Domains and Items	No. (%) Responders in Each Category			
	No. (%) of Respondents	Not Needed (coded as missing)	Needed and Not Available (coded as 0)	Needed and Available (coded as 1)
Classmates				
54. Child encouraged to reach potential from classmates	727 (89)	0 (0)	164 (20)	563 (69)
56. Child receives emotional support from classmates	724 (89)	0 (0)	149 (18)	575 (70)
59. Classmates have positive attitude toward child	758 (93)	0 (0)	58 (7)	700 (86)

*Includes question on need.

Comparison With Other Studies

Two quantitative studies found geographical variation in the participation of children with CP,^{28,29} but they did not examine which were the relevant environmental features.

Forsyth et al³⁰ found in a national study that the participation of severely disabled children was influenced by their environment, especially by social support, physical access, and transport. King et al³¹ undertook a study of leisure and recreation participation in children with physical impairments, using the instrument Craig Hospital Inventory of Environmental Factors (CHIEF)³² to measure environment. Using a structural equation model, the authors found that family cohesion, supportive relationships, and environmental access had only small indirect effects on participation; the indirect effect being mediated through personal factors such as the child's preferences and emotional state. However, the small effect detected may be partly because the CHIEF generates a score based on the frequency and extent of perceived environmental barriers and therefore yields a subjective measure of the influence of environment on participation rather than a direct measure of the environment; this measure may reflect differing expectations of participation rather than actual environmental barriers.³³

A study of adults with spinal cord injury found that environment, as measured by the CHIEF, explained 4% or less of the variation in domains of participation.³⁴ A study of adults with mobility limitations³⁵ found a moderate relationship between participation in leisure activities and the community environment; however, the environmental questionnaire used (Facilitators and Barriers Survey/Mobility)³⁶ was similar to the CHIEF in that it generated a subjective measure of environment.

Our study is a cross-sectional analysis, and therefore the association between environment and participation cannot be interpreted as a causal relationship without other supporting evidence, ideally, a longitudinal study that assesses the impact on participation of environmental change. However, the consistency between the results of our study and those of other quantitative and qualitative studies⁵ suggests that the statistically significant associations we have found may indeed reflect a causal effect of environment on participation. Furthermore, considering the independence of our measures of environment and participation, and our adjustment for individual-level factors, we think our estimates of the magnitude of this effect improve on previous studies.

Implications for Practice

While both severity of impairment and lack of needed environmental features are associated with reduced participation,³⁰ there is speculation about whether environment or impairment should be the target for change—addressing the former assumes a social model of disability, whereas addressing the latter is consistent with a medical model. Our results suggest that, at the very least, the effects of such interventions should be compared. It is now being seriously questioned³⁷ whether medical therapies, such as stretching, improve a child's function, let alone their participation.

The first randomized controlled trial in this field suggests that environmental adjustment for children with physical impairment is at least as effective (as judged by self-help skills and mobility) as conventional therapeutic interventions that aim to change the child.^{38,39}

Implications for Research

The concepts of participation and environment, the instruments for measuring them, and the methods of modeling them are still being refined but already offer improved opportunities to understand which components of the environment most influence participation. To ensure an objective assessment of the relationship between participation and environment, it is essential that separate instruments are used to measure these concepts. Although we used structural equations to assess relationships between latent variables, some domains of participation and environment might be better if defined explicitly rather than representing them as latent variables. This would involve value judgments, which should ideally be made by parents and young people and would therefore have meaning to them in their daily lives.

Study Strengths

We have addressed recent recommendations⁴⁰ regarding the investigation of the relationship between participation and environment: we undertook analyses based on domains, used multi-variable models that included personal factors—such as pain and impairment—influencing participation, and used instruments that captured participation and environment separately. In using the ECEQ, we analyzed whether an item was available or not, hence avoiding incorporating aspects of participation. We modified the scoring of the Assessment of Life Habits; therefore, whether assistance was needed or not, it did not influence the participation score.

The findings of the study are likely to be generally valid for children with CP, because we sampled from population-based registries of children with CP and included children with all levels of impairment. Furthermore, such children often have other associated impairments of learning, communication, and epilepsy, and therefore are exemplars of the wider population of disabled children.

Study Limitations

It is an intrinsic feature of structural equation modeling that different models are likely to fit the data²³; for example, some environmental domains were highly correlated and therefore it is possible that different domains could have generated equally valid models. We encountered statistical difficulties modeling some environmental domains (eg, the physical environment at home, as discussed in [appendix 1](#)). Thus, the use of formative (cause) indicators to measure environment should be considered, because some elements of environment may not reflect an underlying factor and might be better viewed as cumulatively defining an

Table 3: Distribution of Responses to Assessment of Life Habits Items (N=818)

Assessment of Life Habits Domains and Items	No. (%) of Respondents	No. (%) Responders in Each Category			
		Item Achieved		Item Not Achieved	
		Without Difficulty (coded as 0)	With Difficulty (coded as 1)	Too Difficult (coded as 2)	Other Reasons (coded as missing)
Daily activities					
Mealtimes					
1. Eating meals*	815 (100)	518 (63)	297 (36)	0 (0)	0 (0)
16. Selecting the type and amount of food desired	802 (98)	548 (67)	94 (11)	94 (11)	66 (8)
17. Taking part in preparing meals	810 (99)	267 (33)	148 (18)	230 (28)	165 (20)
18. Eating out at restaurants, cafes, or fast food outlets	810 (99)	508 (62)	208 (25)	70 (9)	24 (3)
Health hygiene					
2. Getting in and out of bed*	818 (100)	563 (69)	255 (31)	0 (0)	0 (0)
19. Getting a good sleep	801 (98)	567 (69)	107 (13)	111 (14)	16 (2)
20. Doing physical exercise for health	810 (99)	366 (45)	310 (38)	90 (11)	44 (5)
21. Doing leisure pursuits for relaxation	811 (99)	690 (84)	82 (10)	12 (1)	27 (3)
Personal care					
3. Attending to personal hygiene*	815 (100)	391 (48)	424 (52)	0 (0)	0 (0)
4. Toileting at home*	812 (99)	495 (61)	317 (39)	0 (0)	0 (0)
5. Toileting away from home*	805 (98)	430 (53)	375 (46)	0 (0)	0 (0)
6. Dressing and undressing upper half of body*	815 (100)	358 (44)	457 (56)	0 (0)	0 (0)
7. Dressing and undressing lower half of body*	813 (99)	338 (41)	475 (58)	0 (0)	0 (0)
8. Taking part in their own health care*	805 (98)	476 (58)	329 (40)	0 (0)	0 (0)
9. Using services provided by the local doctor, hospital, or rehabilitation center*	799 (98)	522 (64)	277 (34)	0 (0)	0 (0)
22. Putting on and taking off his/her own aids	812 (99)	233 (28)	100 (12)	265 (32)	214 (26)
Home life					
10. Entering and leaving home*	815 (100)	560 (68)	255 (31)	0 (0)	0 (0)
11. Moving around the home*	816 (100)	619 (76)	197 (24)	0 (0)	0 (0)
31. Helping with housework	817 (100)	301 (37)	145 (18)	259 (32)	112 (14)
32. Helping in the garden or backyard	816 (100)	228 (28)	110 (13)	264 (32)	214 (26)
33. Managing common household things, eg, tables, light switches, cupboards, doors	812 (99)	522 (64)	116 (14)	169 (21)	5 (1)
34. Moving about just outside the home	813 (99)	517 (63)	223 (27)	65 (8)	8 (1)
Mobility					
12. Moving about on streets and pavements*	811 (99)	410 (50)	401 (49)	0 (0)	0 (0)
35. Moving about on slippery or uneven surfaces	813 (99)	261 (32)	355 (43)	193 (24)	4 (0)
36. Riding a bicycle, tricycle, scooters, rollerblades, wheelchair for pleasure, etc	814 (100)	385 (47)	223 (27)	174 (21)	32 (4)
37. Traveling as a passenger in vehicles	814 (100)	615 (75)	183 (22)	8 (1)	8 (1)
Social roles					
Responsibilities					
38. Recognizing money and using it correctly	816 (100)	314 (38)	118 (14)	306 (37)	78 (10)
39. Managing pocket money	818 (100)	291 (36)	74 (9)	302 (37)	151 (18)
40. Using a bank or post office account	815 (100)	101 (12)	25 (3)	278 (34)	411 (50)
41. Shopping or doing errands	812 (99)	300 (37)	88 (11)	307 (38)	117 (14)
42. Respecting other people's property and rights	808 (99)	547 (67)	88 (11)	159 (19)	14 (2)
43. Taking responsibility for him/herself	814 (100)	372 (45)	118 (14)	282 (34)	42 (5)
44. Supporting family members as needed	815 (100)	513 (63)	87 (11)	177 (22)	38 (5)
Relationships					
45. Maintaining a loving relationship with parents	814 (100)	760 (93)	45 (6)	8 (1)	1 (0)
46. Maintaining a loving relationship with other members of family living at home	815 (100)	635 (78)	57 (7)	7 (1)	116 (14)
47. Maintaining a loving or social relationship with other relatives	811 (99)	729 (89)	45 (6)	17 (2)	20 (2)
48. Maintaining friendly links with other young people at school or at leisure	810 (99)	626 (77)	127 (16)	43 (5)	14 (2)
49. Maintaining friendly links with other adults	813 (99)	719 (88)	71 (9)	19 (2)	4 (0)
School					
13. Getting to school, entering and moving about within the school and yard*	804 (98)	539 (66)	265 (32)	0 (0)	0 (0)
14. Taking part in lessons, assignments and assessments at school*	801 (98)	434 (53)	367 (45)	0 (0)	0 (0)

Table 3 (Cont'd): Distribution of Responses to Assessment of Life Items (N=818)

Assessment of Life Habits Domains and Items	No. (%) of Respondents	No. (%) Responders in Each Category			
		Item Achieved		Item Not Achieved	
		Without Difficulty (coded as 0)	With Difficulty (coded as 1)	Too Difficult (coded as 2)	Other Reasons (coded as missing)
15. Using school facilities*	796 (97)	518 (63)	278 (34)	0 (0)	0 (0)
52. Taking part in a range of extra classes including physical education, music, etc	755 (92)	270 (33)	144 (18)	154 (19)	187 (23)
53. Doing homework	807 (99)	295 (36)	285 (35)	75 (9)	152 (19)
54. Taking part in activities organized by the school	806 (99)	517 (63)	252 (31)	15 (2)	22 (3)
Recreation					
55. Playing sports or outdoor games	811 (99)	326 (40)	233 (28)	174 (21)	78 (10)
56. Playing nonsporting games	816 (100)	472 (58)	177 (22)	138 (17)	29 (4)
57. Going and watching sports events	813 (99)	246 (30)	81 (10)	128 (16)	358 (44)
58. Taking part in artistic, cultural, or craft activities	806 (99)	329 (40)	167 (20)	139 (17)	171 (21)
59. Going and watching artistic or cultural events	814 (100)	472 (58)	186 (23)	93 (11)	63 (8)
60. Taking part in tourist activities	812 (99)	455 (56)	292 (36)	44 (5)	21 (3)
61. Getting to and moving about within local recreational facilities	801 (98)	399 (49)	167 (20)	148 (18)	87 (11)
62. Taking part in the activities in local recreational facilities	799 (98)	285 (35)	135 (17)	189 (23)	190 (23)

*Nondiscretionary item, assumed to be achieved by all children.

environmental domain.^{23,33} However, the statistically significant relationships between participation and environmental domains correspond to hypotheses that were stated prior to statistical analysis; and the multiple imputations generate confidence intervals that reflect the uncertainty because of missing data. Hence, we have confidence that the significant associations are unlikely to be chance findings.

CONCLUSIONS

While the UN conventions, ICF-CY, and social model of disability previously discussed emphasize the need to adjust the environment, the evidence that this might help was limited. Our study supports the view that environmental adjustment does indeed promote participation.

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APPENDIX 1: FURTHER DETAILS OF STATISTICAL METHODS

Variable Types

The following variables were treated as ordered categorical variables: ECEQ responses (2 categories), Assessment of Life Habits responses (2 or 3 categories), levels of walking ability (5 categories), fine motor function (5 categories), intelligence quotient (3 categories), feeding ability (3 categories), seizures (5 categories), and communication ability (4 categories). Frequency and severity of pain were treated as continuous variables, because this resulted in a better model fit.

Model Modifications

Models were adjusted until the fit indices were satisfactory, by inspecting modification indices and omitting items or add-

Table 4: Relationship Between Participation in Daily Activities and Environment

Participation Domain (Life-H)	Environmental Domain (ECEQ)	Standardized Regression Coefficients Relating Participation to:						RMSEA	CFI	% Variance Explained by Environment [†]
		Environment		Impairment b (95% CI)*	Pain b (95% CI)*					
		b (95% CI)*	P							
Mealtimes	Physical environment: home	0.22 (0.12 to 0.32)	0.001	-0.92 (-0.87 to -0.96)	Omitted (not significant)		0.048	0.992	24%	
Health hygiene	Physical environment: home	0.22 (0.05 to 0.38)	0.011	-0.77 (-0.69 to -0.84)	-0.17 (-0.25 to -0.09)		0.048	0.986	14%	
Personal care	Physical environment: home	0.33 (0.22 to 0.43)	<0.001	-0.64 (-0.57 to -0.71)	-0.13 (-0.20 to -0.05)		0.050	0.988	18%	
Home life	Physical environment: home	0.30 (0.19 to 0.41)	<0.001	-0.82 (-0.77 to -0.88)	-0.14 (-0.24 to -0.04)		0.049	0.990	30%	
Mobility	Transport	0.52 (0.27 to 0.76)	<0.001	-0.53 (-0.45 to -0.62)	Omitted (not significant)		0.046	0.990	25%	
Mobility	Physical environment: community	0.51 (0.29 to 0.74)	<0.001	-0.59 (-0.51 to -0.67)	Omitted (not significant)		0.047	0.983	16%	
Mobility related simultaneously to both transport and physical environment in community:										
Mobility	Transport	0.35 (0.19 to 0.50)	<0.001	-0.56 (-0.49 to -0.64)	Omitted (not significant)		0.040	0.981	29%	
	Physical environment: community	0.16 (0.02 to 0.30)	0.025							

Abbreviations: CI, confidence interval; Life-H, Assessment of Life Habits.

*Standardized regression coefficient (and 95% CI), indicating the change in participation, in SD units, consequent to a change of 1SD in the independent variable. Positive values of b indicate that participation increases with greater availability of environmental items, negative values indicate that participation decreases with increasing severity of impairment and pain.

[†]Percent change in variance between models with and without ECEQ domain, constraining Life-H measurement model without ECEQ to be identical to model with ECEQ.

Table 5: Relationship Between Participation in Social Roles and Environment

Participation Domain (Life-H)	Environmental Domain (ECEQ)	b* (95% CI)	P	RMSEA	CFI
Responsibilities	Physical environment: home	0.20 (0.11 to 0.28)	<0.001	0.050	0.991
	Attitudes: family and friends	0.13 (0.06 to 0.19)	<0.001	0.044	0.991
	Attitudes: teachers and therapists	0.06 (-0.01 to 0.12)	0.122	0.056	0.985
	Attitudes: classmates	0.09 (0.02 to 0.16)	0.008	0.060	0.988
	Social support: home	0.35 (0.19 to 0.50)	<0.001	0.042	0.993
Relationships	Social support: community	0.18 (0.07 to 0.29)	0.001	0.064	0.976
	Attitudes: family and friends	0.22 (0.10 to 0.33)	<0.001	0.037	0.989
	Attitudes: teachers and therapists	0.08 (-0.04 to 0.19)	0.185	0.047	0.981
School	Attitudes: classmates	0.35 (0.25 to 0.46)	0.002	0.047	0.988
	Physical environment: school	0.19 (-0.07 to 0.44)	0.148	0.072	0.964
	Attitudes: teachers and therapists	0.32 (0.23 to 0.41)	<0.001	0.063	0.961
Recreation	Attitudes: classmates	0.12 (0.02 to 0.22)	0.020	0.076	0.964
	Transport	0.26 (0.16 to 0.36)	<0.001	0.057	0.982
	Attitudes: family and friends	0.14 (0.06 to 0.23)	0.001	0.048	0.984
	Social support: home	0.35 (0.20 to 0.50)	<0.001	0.045	0.987
	Social support: community	0.30 (0.19 to 0.41)	<0.001	0.064	0.967

Abbreviations: CI, confidence interval; Life-H, Assessment of Life Habits.

NOTE. Models considered each environmental domain independently. All models included impairment and pain.

*Standardized regression coefficient (and 95% CI), indicating the change in participation, in SD units, consequent to a change of 1SD in environment. Positive values of b indicate that participation increases with greater availability of environmental items.

ing correlations as appropriate. The modification indices give the expected drop in chi-square if the parameter is freely estimated. Items associated with very high modification indices

were considered for omission from the models; for all such items, responses for nearly all children were in 1 category and therefore the items contributed very little information to the

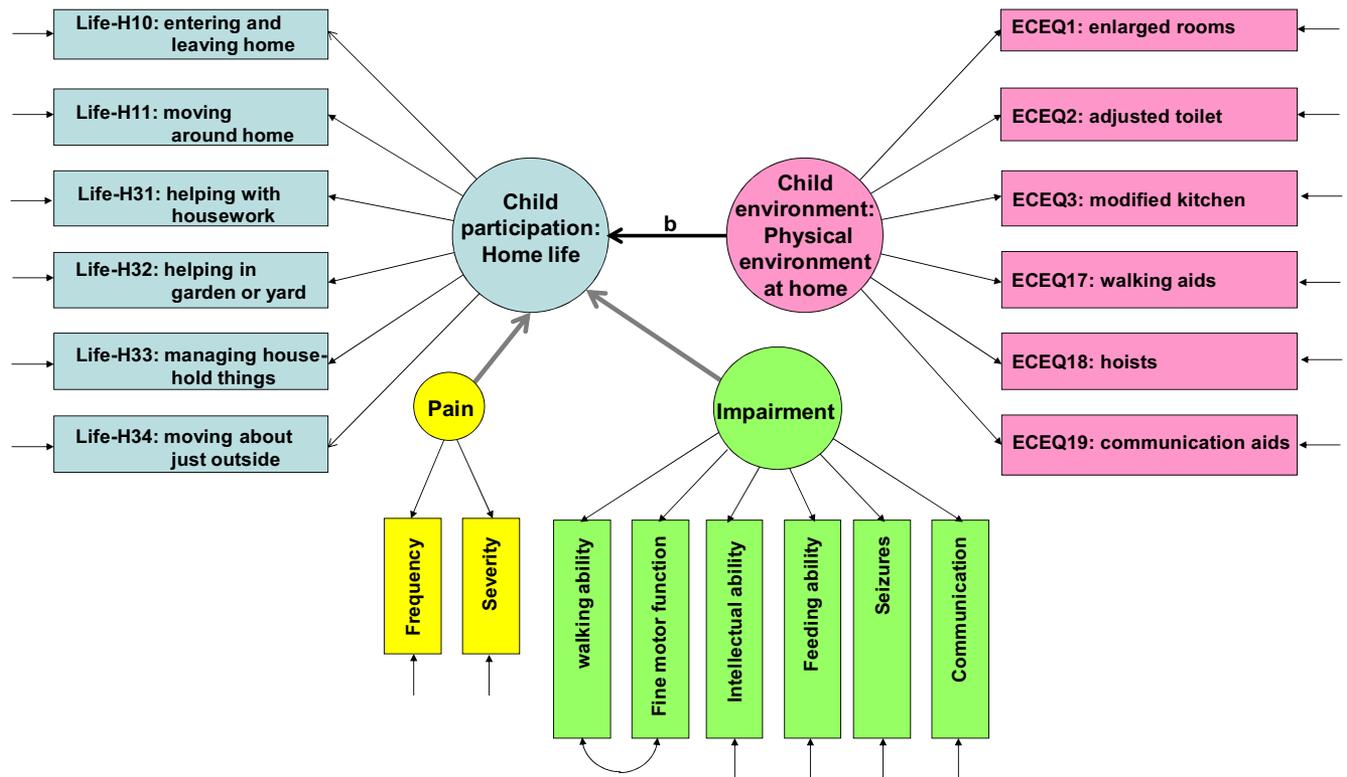


Fig 1. Structural equation model used for the hypothesized association between the child's physical environment at home and participation in home life. Circles represent latent variables. Rectangles represent observed variables: Assessment of Life Habits items, ECEQ items, types of impairments, and pain measures. Straight arrows connecting circles and/or rectangles represent linear relations. The variable at the tail of the arrow is assumed to influence the variable at the head of the arrow. Curved arrows represent correlations. Short arrows pointing at rectangles represent residual variability. b is the regression coefficient relating participation to environment; it is the main parameter of interest. The estimated values of b for the hypothesized associations of participation domains and environmental domains are reported in tables 4 to 6. Abbreviation: Life-H, Assessment of Life Habits.

Table 6: Relationship Between Participation in Social Roles and Environment: Final Models

Participation Domain (Life-H)	Environmental Domain (ECEQ)	Standardized Regression Coefficients Relating Participation to:				RMSEA	CFI	% Variance Explained by Environment [†]
		Environment		Impairment b (95% CI)*				
		b (95% CI)*	P					
Responsibilities	Social support: home	0.35 (0.19 to 0.50)	<0.001	-0.96 (-0.88 to -1.03)	0.044	0.994	52%	
Relationships	Attitudes: classmates	0.36 (0.24 to 0.48)	<0.001	-0.51 (-0.42 to -0.59)	0.051	0.990	19%	
School	Attitudes: teachers and therapists	0.33 (0.24 to 0.43)	<0.001	-0.55 (-0.48 to -0.63)	0.048	0.982	15%	
Recreation	Transport	0.24 (0.14 to 0.34)	<0.001	-0.73 (-0.66 to -0.77)	0.043	0.986	25%	
	Attitudes: family and friends	0.11 (0.03 to 0.19)	0.011					

NOTE. Models included environmental domains that were simultaneously significant. Pain was not significant in any models.

Abbreviations: CI, confidence interval; Life-H, Assessment of Life Habits.

*Standardized regression coefficient (and 95% CI), indicating the change in participation, in SD units, consequent to a change of 1SD in the independent variable. Positive values of b indicate that participation increases with greater availability of environmental items, negative values indicate that participation decreases with increasing severity of impairment.

[†]Percentage change in variance between models with and without ECEQ domain, constraining Life-H measurement model without ECEQ to be identical to model with ECEQ.

model. Parameters with modification indices over 30 were considered for inclusion in the model only if they were pragmatically justified, for example correlation of the Assessment of Life Habits items: dressing and undressing upper half of body with dressing and undressing lower half of body, and if they helped to improve the model fit such that the RMSEA was $\leq .05$ and the CFI was $> .95$. These model modifications are subsequently described in detail.

ECEQ: Physical Environment at Home

When this domain was based on all relevant items (1 (enlarged rooms), 2 (adapted toilet), 3 (modified kitchen), 17 (walking aids), 18 (hoists), 19 (communication aids)), item 2 had a negative residual variance. We therefore omitted items 17 and 18, because they captured little information—walking aids (item 17) were available to almost all children who needed them and hoists (item 18) were needed by less than one third of the children. An alternative analysis, basing the measure of the physical environment at home on items 1, 3, 17, 18, and 19 yielded similar results.

Assessment of Life Habits

Item 22 (putting on and taking off his/her own aids) was omitted from the domain of personal care. This was the only discretionary item in this domain.

Item 46 (maintaining a loving relationship with other members of family living at home) was omitted from the domain of relationships.

Correlations Between Items and Factors

The model assumed correlations between the latent factors, that is, between pain and impairment, pain and environment, impairment and environment, and environmental domains if more than 1 such domain was included.

The following correlations were added to improve the fit of models, where lh* refers to Assessment of Life Habits items and eceq* refers to ECEQ items.

Model of health hygiene \times physical environment home: lh2 (getting in and out of bed) was correlated with walking ability;

Model of personal care \times physical environment home: lh6 (dressing and undressing upper half of body) was correlated with lh7 (dressing and undressing lower half of body);

Model of home life \times physical environment home: lh10 (entering and leaving home) was correlated with lh11 (moving

around the home) and lh34 (moving about just outside the home);

Model of school \times attitudes of teachers and therapists: lh52, lh53, eceq30 (teachers/doctors listen to your views), eceq46 (child has school placement s/he needs) were correlated with the latent factor for impairment.

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