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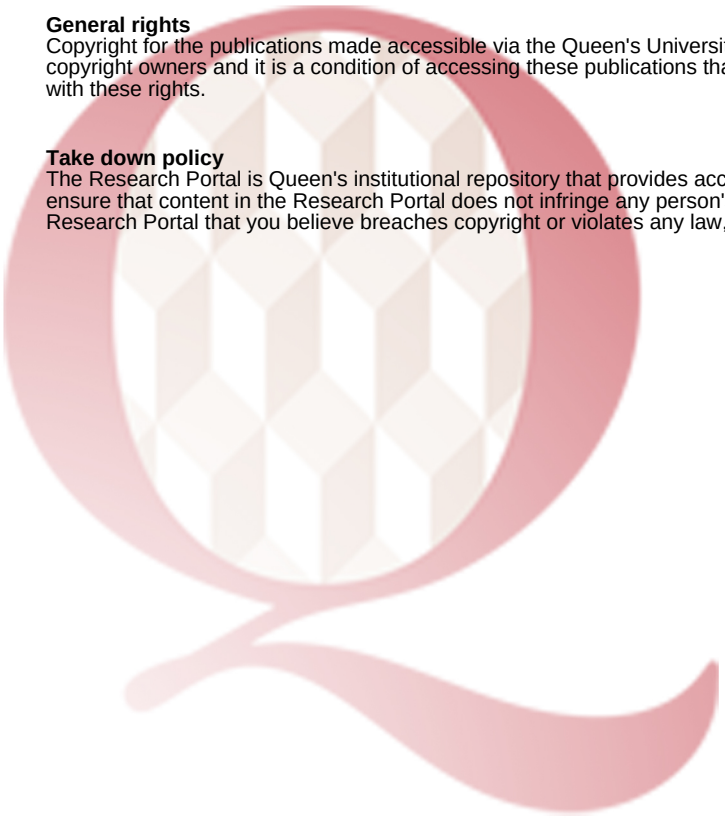

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Association between participation in life situations of children with cerebral palsy and their physical, social and attitudinal environment: a cross-sectional multi-centre European study

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Abstract

Objective: To evaluate how participation of children with cerebral palsy varied with their environment

Design: Home visits to children. Administration of Life-H and European Child Environment Questionnaires. Structural equation modelling 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 registers of children with cerebral palsy

Participants: 1,174 children aged 8-12 years were randomly selected from eight population-based registers of children with cerebral palsy in six European countries. 743 (63%) agreed to participate; one 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 hypothesised 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 ($p<0.01$). Mobility was associated with transport and the 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

Social participation, Environment, Child, Cerebral palsy, Statistical model

List of abbreviations

CFI Comparative Fit Index

CHIEF Craig Hospital Inventory of Environmental Factors

CP Cerebral Palsy

ECEQ European Child Environment Questionnaire

FABS/M Facilitators and Barriers Survey/Mobility

ICF-CY International Classification of Functioning, Disability and Health for Children and Youth

RMSEA Root Mean Square Error of Approximation

SPARCLE Study of PARticipation of Children with cerebral palsy Living in Europe

UN United Nations

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] 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 internal 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 conventions emphasize the importance of participation: the UN Convention on the Rights of the Child[3], 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'; the UN Convention on the Rights of Persons with Disabilities[4] 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 review[5] finding only four 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 relates to their environment in nine European regions. Children with cerebral palsy (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 so 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 participation[9] and environmental access [10] vary by region. By environmental access we mean the social, attitudinal and physical environment in the home, school and community such as adapted toilet at home, encouragement by teachers to reach potential, well integrated healthcare 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 paper is to evaluate the principal hypothesis of SPARCLE: 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 summarised below.

Children were eligible if born between 31/7/1991 and 1/4/1997 and on registers of children with CP 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). The 1,884 eligible children were randomly sampled following stratification by walking ability as recorded when the children were originally recruited to the registers: no functional consequences but walking may not be normal; walking restricted but unaided; walking limited and needs aids; unable to walk)[13].1,174 families were 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 2004/05 by researchers who administered questionnaires to parents to assess their child's environment, participation in everyday activities and social roles, pain, impairments and socio-demographic characteristics.

Impairment and pain

Parents and researchers completed questionnaires together about the child's impairments. These impairments and their severity (gross motor function[14], fine motor skills[15], intellectual ability, seizures, feeding, communication) are shown in Table 1. IQ was classified in three categories: >70 / 50-70 / <50 according to the IQ 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 two items from the Child Health Questionnaire[16] but with the time frame changed from four weeks to one week to be consistent with that used in other

instruments in SPARCLE. The distribution of socio-demographic characteristics, impairment and pain is summarised 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 work[20] in each country participating in SPARCLE. Factor analysis suggested that 51 items could be combined into nine domains[17] which are set out in Table 2. For 37 items (marked * 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; 'Needed and available' = 1. If the

item was 'Not needed', its availability was imputed using multiple imputation (see Statistical methods below).

Measure of child participation

Participation was assessed using Life-H[21] which has been validated in disabled children[21], including those with CP[22]. It comprises 62 items grouped into ten domains covering daily activities and social roles. The nine domains we use in this paper are set out in Table 3 and the tenth domain is communication. We omitted one question about sexual relationships as it was inappropriate to this age group. For 15 items that concern non-discretionary 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 so, 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 Life-H also ask whether the child needs assistance to participate. Our analysis ignored the questions about assistance, as 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 participation and environment could be summarised by a single factor which 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 one.

The structural equation models[23] related specific domains of participation to specific environmental domains, according to our prior hypotheses, while allowing for impairment and pain. We used multiple imputation[25] to impute environmental data that were missing due either to 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 non-availability 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 due to both ordinary sampling variation and to 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 Life-H and ECEQ domains Our main objective was to estimate the magnitude of the regression coefficient (labeled b in Figure 1) relating participation to environment, while adjusting for impairment and pain. Impairment was modeled as a factor expressed through the observed impairments[26] gross motor function, fine motor skills, intellectual ability, seizures, feeding, communication, 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 standard errors and pairwise deletion of missing data. Covariates that were

not statistically significant (Wald p-value >0.05) 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 Life-H responses) or adding correlations between items, or between items and factors, as appropriate (see Appendix).

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-values <0.01 as statistically significant. The final models excluded children with missing data on impairment and pain.

We report results as standardised 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 one standard deviation 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 since we knew from earlier analysis[27] 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 of 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; twelve (1.5%) had missing data on parent-reported pain. For 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 which were not needed ranged from zero (for items 24, 26, 30, 33, 41, 42, 44, 46, 53-55, 57, 59, 60 which were assumed to be needed by all children) to 75% for item 19 (communication aids at home). For Life-H, the proportion of missing responses ranged from zero for item 2 to 8% for item 52 (see Table 3). Responses to Life-H 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 ($p<0.01$) associated with higher participation in mealtimes, personal care and home life; the association with health hygiene was of marginal statistical significance ($p=0.011$). 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 ($p=0.025$). 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 ($RMSEA \leq 0.05$, $CFI>0.95$).

Social roles

As shown in Table 5, most but not all of the hypothesised associations between environment and participation in social roles were statistically significant ($p<0.01$). The following hypothesised 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; 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 as 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 0.81, 0.26, 0.23 and 0.82 respectively; so 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 0.42, so 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 0.59 and 0.44 respectively, so 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 0.22, so 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; both transport and attitudes of family and friends independently predicted participation in recreation. Pain was removed from the final models as it was not statistically significant and correlations were added as appropriate (see Appendix); 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≤0.05, CFI>0.95).

Discussion

Summary of main findings

Our findings support the principal hypothesis of the SPARCLE study 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 ECEQ, accounted for between 14% and 52% of the variation in participation between children.

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[30] 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 al[31] undertook a study of leisure and recreation participation in children with physical impairments, using the instrument 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 CHIEF generates a score based on the frequency and extent of perceived environmental barriers and so 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 CHIEF, explained 4% or less of the variation in domains of participation[34]. A study of adults with mobility limitations[35] found a moderate relationship between participation in leisure activities and the community environment; however, the environmental questionnaire used (FABS/M)[36] was similar to 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 studies[5], 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

Whilst 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 questioned[37] 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 which 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 modelling 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 judgements which should ideally be made by parents and young people and so have meaning to them in their daily lives.

Study strengths

We have addressed recent recommendations[40] regarding the investigation of the relationship between participation and environment; we undertook analyses based on domains; we used

multivariable models that included personal factors – such as pain and impairment – that influenced participation; and we 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; and we modified the scoring of the Life-H so that whether assistance was needed or not 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 registers of children with CP and we included children with all levels of impairment. Furthermore such children often have other associated impairments of learning, communication and epilepsy and so are exemplars of the wider population of disabled children.

Study limitations

It is an intrinsic feature of structural equation modelling that different models are likely to fit the data[23]; for example, some environmental domains were highly correlated so it is possible that different

domains could have generated equally valid models. We encountered statistical difficulties modelling some environmental domains (e.g. the physical environment at home as discussed in the Appendix). 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 environmental domain[23, 33]. However, the statistically significant relationships between participation and environmental domains correspond to hypotheses which were stated prior to statistical analysis; and the multiple imputations generate confidence intervals that reflect the uncertainty due to missing data. Hence we have confidence that the significant associations are unlikely to be chance findings.

Conclusions

Whilst the UN conventions, ICF-CY and social model of disability discussed in our introduction emphasise 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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Suppliers List

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Legend for Figure 1

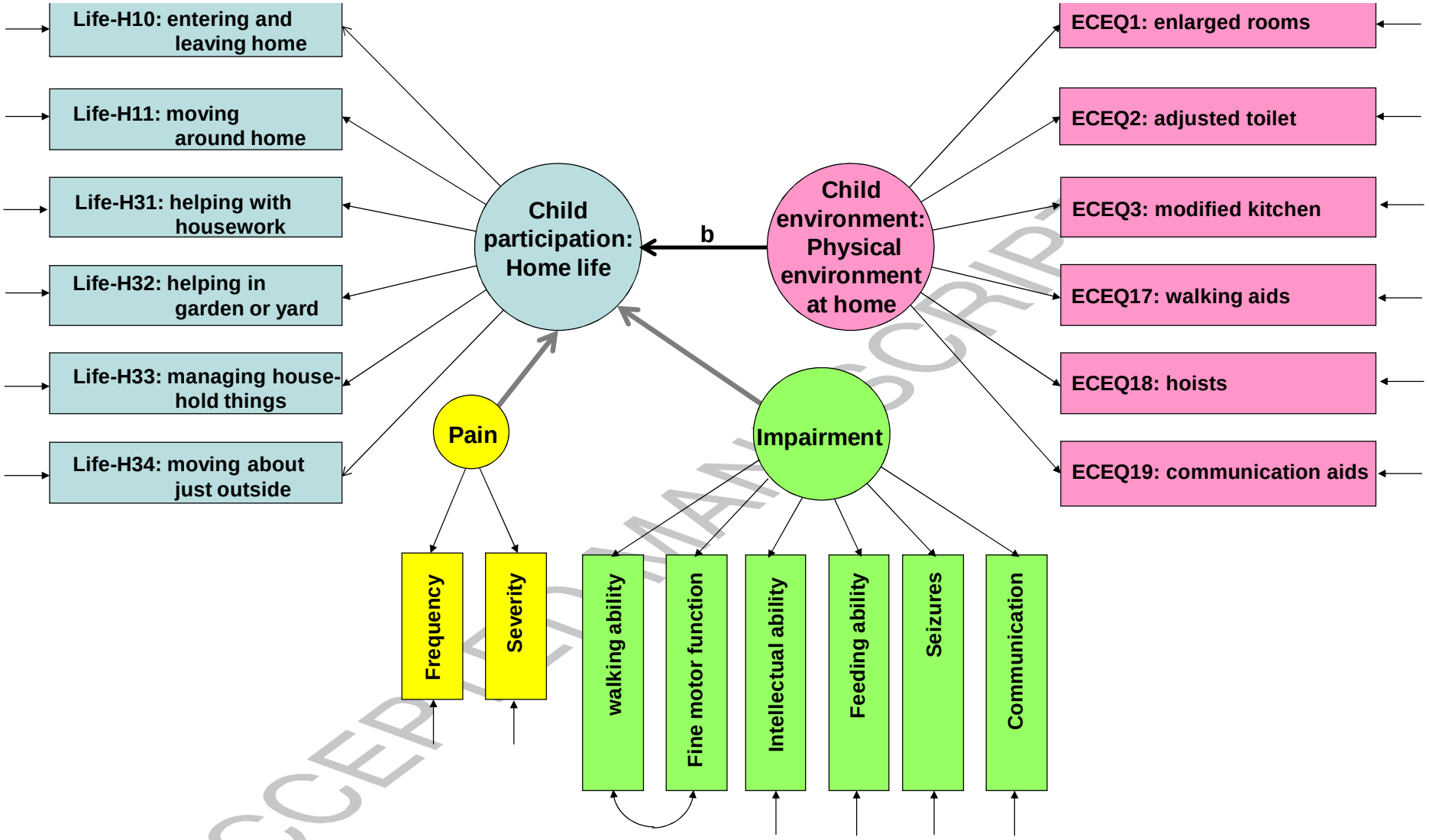
Structural equation model used for the hypothesized association between the child's physical environment at home and participation in home life.

Footnotes:

1 Circles represent latent variables. Rectangles represent observed variables: Life-H items; ECEQ items; types of impairments; 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.

2 ‘b’ is the regression coefficient relating participation to environment; it is the main parameter of interest. The estimated values of b for the hypothesised associations of participation domains and environmental domains are reported in Tables 4, 5 and 6.

Figure



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b is the regression coefficient relating participation to environment; it is the main parameter of interest. The estimated values of b for the hypothesised associations of participation domains and environmental domains are reported in Tables 4, 5 and 6.

Table 1. Summary of distribution of socio-demographic characteristics, impairment and pain (n = 818)

		N	*(%)*
Socio-demographic characteristics			
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%)
Gender			
Boys		484	*(59%)*
Girls		334	*(41%)*
Age in years			
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%)*

	N	*(%)*
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 non-speech 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%)*
Frequency of pain		
None of the time	237	*(29%)*
Once or twice or a few times	414	*(51%)*
More often	155	*(19%)*
Information not available	12	*(1%)*

Table 2 Summary of distribution of responses to European Child Environment Questionnaire items (n=818)

	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 centre	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)*

Table 3 Distribution of responses to Life-H items (n=818)

		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 centre	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 e.g. 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 Recognising 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, etc.	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)*
*	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 organised 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 non-sporting 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)*

* = Non-discretionary item, assumed to be achieved by all children

Table 4 Relationship between participation in daily activities and environment.

Participation domain (Life-H)	Environmental domain (ECEQ)	Standardised regression coefficients relating participation to: Environment b	Environment (95%CI)*	Environment p	Impairment b	Impairment (95%CI)*	Pain b	Pain (95%CI)*	RMSEA†	CFI‡	% variance explained by environment§
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							

* Standardised regression coefficient (and 95% confidence interval), indicating the change in participation, in standard deviation units, consequent to a change of one standard deviation 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.

† Root mean square error of approximation

‡ Comparative fit index

§ % 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.

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

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
	Social support: Community	0.18	(0.07 to 0.29)	0.001	0.064	0.976
Relationships	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
	Attitudes: Classmates	0.35	(0.25 to 0.46)	0.002	0.047	0.988
School	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
	Attitudes: Classmates	0.12	(0.02 to 0.22	0.020	0.076	0.964
Recreation	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

* Standardised regression coefficient (and 95% confidence interval), indicating the change in participation, in standard deviation units, consequent to a change of one standard deviation in environment. Positive values of b indicate that participation increases with greater availability of environmental items.

† Root mean square error of approximation

‡ Comparative fit index

Table 6. Relationship between participation in social roles and environment – final models.

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

Participation domain (Life-H)	Environmental domain (ECEQ)	Standardised regression coefficients relating participation to: Environment b	(95%CI)*	p	Impairment b	(95%CI)*	RMSEA †	CFI ‡	% variance explained by environment §
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					