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

Allan Colver, MD, Ute Thyen, MD, Catherine Arnaud, MD, Eva Beckung, PhD, Jerome Fauconnier, MD, Marco Marcelli, MD, Vicki McManus, MSc, Susan I. Michelsen, MD, Jackie Parkes, PhD, Kathryn Parkinson, PhD, O. Dickinson, PhD


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 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.

© 2012 by the American Congress of Rehabilitation Medicine

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) 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.

Two United Nations (UN) conventions emphasize the importance of participation: Article 23 of the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. The disability rights movement has placed participation at the center of its advocacy to ensure that children with disabilities have access to opportunities and privileges enjoyed by all children. Participation is not an end in itself, but an avenue for realizing potential and building citizenship. Participation is also a human right, as stated in the UN Convention on the Rights of the Child, Article 12: "The child has the right to freedom of thought, conscience, and expression; to hold opinions without interference; and to express these意见 freely without interference."

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) 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.

Two United Nations (UN) conventions emphasize the importance of participation: Article 23 of the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. The disability rights movement has placed participation at the center of its advocacy to ensure that children with disabilities have access to opportunities and privileges enjoyed by all children. Participation is not an end in itself, but an avenue for realizing potential and building citizenship. Participation is also a human right, as stated in the UN Convention on the Rights of the Child, Article 12: "The child has the right to freedom of thought, conscience, and expression; to hold opinions without interference; and to express these opinions freely without interference."
Rights of the Child 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 Disabilities 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 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 (SPARCLE) 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 and that, for children with CP, both participation and environmental access 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. 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 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.

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. 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 severity (gross motor function, fine motor skills, 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, 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), 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, qualitative study, and focus group work in each country participating in SPARCLE. Factor analysis suggested that 51 items could be combined into 9 domains, 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, which has been validated in disabled children, including those with CP. 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.

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 summarized by a single factor that could not be observed directly, but which determined the parents’ responses to the items. 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 models related specific domains of participation to specific environmental domains, according to our prior hypotheses, while allowing for impairment and pain. We used multiple imputation 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.

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 figure 1) relating participation to environment, while adjusting for impairment and pain. Impairment was modeled as a factor expressed through the observed impairments—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 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

<table>
<thead>
<tr>
<th>Country: region</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>France: southeast France</td>
<td>26</td>
<td>3</td>
</tr>
<tr>
<td>France: southwest France</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>Germany: northwest Germany</td>
<td>50</td>
<td>19</td>
</tr>
<tr>
<td>Ireland: southwest Ireland</td>
<td>51</td>
<td>19</td>
</tr>
<tr>
<td>Sweden: west Sweden</td>
<td>12</td>
<td>20</td>
</tr>
<tr>
<td>UK: north England</td>
<td>26</td>
<td>14</td>
</tr>
<tr>
<td>UK: Northern Ireland</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>Denmark: east Denmark</td>
<td>20</td>
<td>15</td>
</tr>
<tr>
<td>Italy: central Italy</td>
<td>20</td>
<td>10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age (y)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>11</td>
<td>21</td>
</tr>
<tr>
<td>9</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>10</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>11</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>12</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>13</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boys</td>
<td>48</td>
<td>59</td>
</tr>
<tr>
<td>Girls</td>
<td>33</td>
<td>41</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Intellectual impairment</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>None or mild (IQ &gt; 70)</td>
<td>22</td>
<td>47</td>
</tr>
<tr>
<td>Moderate (IQ 50–70)</td>
<td>18</td>
<td>23</td>
</tr>
<tr>
<td>Severe (IQ &lt; 50)</td>
<td>22</td>
<td>24</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Seizures</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No seizures in previous year</td>
<td>5</td>
<td>79</td>
</tr>
<tr>
<td>Seizures in previous year</td>
<td>17</td>
<td>20</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeding</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No problems</td>
<td>58</td>
<td>71</td>
</tr>
<tr>
<td>Feeds orally with difficulty</td>
<td>12</td>
<td>22</td>
</tr>
<tr>
<td>Partial or complete feeding by tube</td>
<td>4</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal speech</td>
<td>48</td>
<td>57</td>
</tr>
<tr>
<td>Difficulty but uses speech</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>Uses nonspeech for formal communication</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>No formal communication</td>
<td>21</td>
<td>15</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parental report of child pain in the previous week</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>24</td>
<td>29</td>
</tr>
<tr>
<td>Very mild or mild</td>
<td>35</td>
<td>43</td>
</tr>
<tr>
<td>Moderate, severe, or very severe</td>
<td>22</td>
<td>26</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency of pain</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>None of the time</td>
<td>23</td>
<td>29</td>
</tr>
<tr>
<td>Once or twice or a few times</td>
<td>41</td>
<td>51</td>
</tr>
<tr>
<td>More often</td>
<td>15</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Information not available</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information not available</td>
<td>12</td>
<td>1</td>
</tr>
</tbody>
</table>

Abbreviation: IQ, intelligence quotient.
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, 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 analysis 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 she 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 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 ≤ .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 responsibilities, 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 ≤ .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)

<table>
<thead>
<tr>
<th>ECEQ Domains and Items</th>
<th>No. (%) of Respondents</th>
<th>No. (%) Responders in Each Category</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Not Needed (coded as missing)</td>
</tr>
<tr>
<td><strong>Physical environment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Home</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Enlarged rooms at home*</td>
<td>815 (100)</td>
<td>399 (49)</td>
</tr>
<tr>
<td>2. Adapted toilet at home*</td>
<td>815 (100)</td>
<td>476 (58)</td>
</tr>
<tr>
<td>3. Modified kitchen at home*</td>
<td>817 (100)</td>
<td>584 (71)</td>
</tr>
<tr>
<td>17. Walking aids*</td>
<td>815 (100)</td>
<td>395 (48)</td>
</tr>
<tr>
<td>18. Hoists at home*</td>
<td>817 (100)</td>
<td>578 (71)</td>
</tr>
<tr>
<td>19. Communication aids at home*</td>
<td>818 (100)</td>
<td>611 (75)</td>
</tr>
<tr>
<td><strong>School</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>47. Ramps at school*</td>
<td>803 (98)</td>
<td>390 (48)</td>
</tr>
<tr>
<td>48. Adapted toilets at school*</td>
<td>803 (98)</td>
<td>394 (48)</td>
</tr>
<tr>
<td>49. Lifts at school*</td>
<td>802 (98)</td>
<td>526 (64)</td>
</tr>
<tr>
<td>50. Communication aids at school*</td>
<td>798 (98)</td>
<td>499 (61)</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Ramps in public places*</td>
<td>816 (100)</td>
<td>366 (45)</td>
</tr>
<tr>
<td>5. Adapted toilets in public places*</td>
<td>813 (99)</td>
<td>445 (54)</td>
</tr>
<tr>
<td>6. Lifts in public places*</td>
<td>815 (100)</td>
<td>272 (33)</td>
</tr>
<tr>
<td>8. Suitable doorways in public places*</td>
<td>817 (100)</td>
<td>359 (44)</td>
</tr>
<tr>
<td>9. Room in public places to move around*</td>
<td>816 (100)</td>
<td>341 (42)</td>
</tr>
<tr>
<td>10. Smooth pavements in town or village center*</td>
<td>815 (100)</td>
<td>203 (25)</td>
</tr>
<tr>
<td>11. Adequate vehicle*</td>
<td>818 (100)</td>
<td>210 (26)</td>
</tr>
<tr>
<td>12. Accessible car parking*</td>
<td>816 (100)</td>
<td>293 (36)</td>
</tr>
<tr>
<td><strong>Transport</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Adequate bus service*</td>
<td>814 (100)</td>
<td>478 (58)</td>
</tr>
<tr>
<td>14. Accessible buses*</td>
<td>814 (100)</td>
<td>476 (58)</td>
</tr>
<tr>
<td>15. Accessible train services*</td>
<td>813 (99)</td>
<td>523 (64)</td>
</tr>
<tr>
<td>16. Accessible taxis*</td>
<td>816 (100)</td>
<td>431 (53)</td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Home</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Receive grants for equipment*</td>
<td>816 (100)</td>
<td>280 (34)</td>
</tr>
<tr>
<td>21. Receive grants for home modifications*</td>
<td>805 (98)</td>
<td>430 (53)</td>
</tr>
<tr>
<td>22. Receive grants for holidays*</td>
<td>814 (100)</td>
<td>348 (43)</td>
</tr>
<tr>
<td>23. Information about financial benefits*</td>
<td>815 (100)</td>
<td>90 (11)</td>
</tr>
<tr>
<td>36. Helper or assistant at home*</td>
<td>817 (100)</td>
<td>505 (62)</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Suitable leisure facilities</td>
<td>781 (95)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>29. Child receives physical help from people in public places*</td>
<td>812 (99)</td>
<td>318 (39)</td>
</tr>
<tr>
<td>33. Health service staff coordinate work well</td>
<td>803 (98)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>34. Social services coordinate work well*</td>
<td>799 (98)</td>
<td>460 (56)</td>
</tr>
<tr>
<td>35. Child looked after elsewhere for few days*</td>
<td>816 (100)</td>
<td>495 (61)</td>
</tr>
<tr>
<td>38. Parent support groups in area*</td>
<td>810 (99)</td>
<td>426 (52)</td>
</tr>
<tr>
<td>39. Counseling available*</td>
<td>805 (98)</td>
<td>264 (32)</td>
</tr>
<tr>
<td>42. People in public places have positive attitude toward child</td>
<td>803 (98)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Attitudes</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family and friends</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Emotional support from wider family/friends</td>
<td>811 (99)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>28. Physical help from wider family/friends*</td>
<td>813 (99)</td>
<td>187 (23)</td>
</tr>
<tr>
<td>31. Child allowed extra time at home*</td>
<td>813 (99)</td>
<td>153 (19)</td>
</tr>
<tr>
<td>37. Family/friends look after child for a few hours*</td>
<td>817 (100)</td>
<td>248 (30)</td>
</tr>
<tr>
<td>41. Wider family and friends have positive attitude toward child</td>
<td>810 (99)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>44. Child encouraged to reach potential from wider family/friends</td>
<td>809 (99)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Teachers and therapists</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Teachers/doctors listen to your views</td>
<td>811 (99)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>46(a.) Child has school placement s/he needs</td>
<td>798 (98)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>51. Special staff help child in school*</td>
<td>805 (98)</td>
<td>127 (16)</td>
</tr>
<tr>
<td>52. Child allowed extra time at school*</td>
<td>773 (94)</td>
<td>120 (15)</td>
</tr>
<tr>
<td>53. Child encouraged to reach potential from teachers/therapists</td>
<td>794 (97)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>55. Child receives emotional support from teachers/therapists</td>
<td>774 (95)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>60. Teachers have understanding of medical condition</td>
<td>788 (96)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
Comparison With Other Studies

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

Forsyth et al 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 undertook a study of leisure and recreation participation in children with physical impairments, using the instrument Craig Hospital Inventory of Environmental Factors (CHIEF) 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.

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. A study of adults with mobility limitations found a moderate relationship between participation in leisure activities and the community environment; however, the environmental questionnaire used (Facilitators and Barriers Survey/Mobility) 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 in leisure activities and the community environment; however, the environmental questionnaire used (Facilitators and Barriers Survey/Mobility) 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 in leisure activities and the community environment; however, the environmental questionnaire used (Facilitators and Barriers Survey/Mobility) was similar to the CHIEF in that it generated a subjective measure of environment.

Implications for Practice

While both severity of impairment and lack of needed environmental features are associated with reduced participation, 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 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.

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 recommendations 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 data; 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)

<table>
<thead>
<tr>
<th>Assessment of Life Habits Domains and Items</th>
<th>No. (%) of Respondents</th>
<th>Without Difficulty (coded as 0)</th>
<th>With Difficulty (coded as 1)</th>
<th>Too Difficult (coded as 2)</th>
<th>Other Reasons (coded as missing)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Daily activities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mealtimes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Eating meals*</td>
<td>815 (100)</td>
<td>518 (63)</td>
<td>297 (36)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>16. Selecting the type and amount of food desired</td>
<td>802 (98)</td>
<td>548 (67)</td>
<td>94 (11)</td>
<td>94 (11)</td>
<td>66 (8)</td>
</tr>
<tr>
<td>17. Taking part in preparing meals</td>
<td>810 (99)</td>
<td>267 (33)</td>
<td>148 (18)</td>
<td>230 (28)</td>
<td>165 (20)</td>
</tr>
<tr>
<td>18. Eating out at restaurants, cafes, or fast food outlets</td>
<td>810 (99)</td>
<td>508 (62)</td>
<td>208 (25)</td>
<td>70 (9)</td>
<td>24 (3)</td>
</tr>
<tr>
<td><strong>Health hygiene</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Getting in and out of bed*</td>
<td>818 (100)</td>
<td>563 (69)</td>
<td>255 (31)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>19. Getting a good sleep</td>
<td>801 (98)</td>
<td>567 (69)</td>
<td>107 (13)</td>
<td>111 (14)</td>
<td>16 (2)</td>
</tr>
<tr>
<td>20. Doing physical exercise for health</td>
<td>810 (99)</td>
<td>366 (45)</td>
<td>310 (38)</td>
<td>90 (11)</td>
<td>44 (5)</td>
</tr>
<tr>
<td>21. Doing leisure pursuits for relaxation</td>
<td>811 (99)</td>
<td>690 (84)</td>
<td>82 (10)</td>
<td>12 (1)</td>
<td>27 (3)</td>
</tr>
<tr>
<td><strong>Personal care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Attending to personal hygiene*</td>
<td>815 (100)</td>
<td>391 (48)</td>
<td>424 (52)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>4. Toileting at home*</td>
<td>812 (99)</td>
<td>495 (61)</td>
<td>317 (39)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>5. Toileting away from home*</td>
<td>805 (98)</td>
<td>430 (53)</td>
<td>375 (46)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>6. Dressing and undressing upper half of body*</td>
<td>810 (99)</td>
<td>358 (44)</td>
<td>457 (56)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>7. Dressing and undressing lower half of body*</td>
<td>813 (99)</td>
<td>338 (41)</td>
<td>475 (58)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>8. Taking part in their own health care*</td>
<td>805 (98)</td>
<td>476 (58)</td>
<td>329 (40)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>9. Using services provided by the local doctor, hospital, or rehabilitation center*</td>
<td>799 (98)</td>
<td>522 (64)</td>
<td>277 (34)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>22. Putting on and taking off his/her own aids</td>
<td>812 (99)</td>
<td>233 (28)</td>
<td>100 (12)</td>
<td>265 (32)</td>
<td>214 (26)</td>
</tr>
<tr>
<td><strong>Home life</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Entering and leaving home*</td>
<td>815 (100)</td>
<td>560 (68)</td>
<td>255 (31)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>11. Moving around the home*</td>
<td>816 (100)</td>
<td>619 (76)</td>
<td>197 (24)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>31. Helping with housework</td>
<td>817 (100)</td>
<td>301 (37)</td>
<td>145 (18)</td>
<td>259 (32)</td>
<td>112 (14)</td>
</tr>
<tr>
<td>32. Helping in the garden or backyard</td>
<td>816 (100)</td>
<td>228 (28)</td>
<td>110 (13)</td>
<td>264 (32)</td>
<td>214 (26)</td>
</tr>
<tr>
<td>33. Managing common household things, eg, tables, light switches, cupboards, doors</td>
<td>812 (99)</td>
<td>522 (64)</td>
<td>116 (14)</td>
<td>169 (21)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>34. Moving about just outside the home</td>
<td>813 (99)</td>
<td>517 (63)</td>
<td>223 (27)</td>
<td>65 (8)</td>
<td>8 (1)</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Moving about on streets and pavements*</td>
<td>811 (99)</td>
<td>410 (50)</td>
<td>401 (49)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>35. Moving about on slippery or uneven surfaces</td>
<td>813 (99)</td>
<td>261 (32)</td>
<td>355 (43)</td>
<td>193 (24)</td>
<td>4 (0)</td>
</tr>
<tr>
<td>36. Riding a bicycle, tricycle, scooters, rollerblades, wheelchair for pleasure, etc</td>
<td>814 (100)</td>
<td>385 (47)</td>
<td>223 (27)</td>
<td>174 (21)</td>
<td>32 (4)</td>
</tr>
<tr>
<td>37. Traveling as a passenger in vehicles</td>
<td>814 (100)</td>
<td>615 (75)</td>
<td>183 (22)</td>
<td>8 (1)</td>
<td>8 (1)</td>
</tr>
<tr>
<td><strong>Social roles</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Recognizing money and using it correctly</td>
<td>816 (100)</td>
<td>314 (38)</td>
<td>118 (14)</td>
<td>306 (37)</td>
<td>78 (10)</td>
</tr>
<tr>
<td>39. Managing pocket money</td>
<td>818 (100)</td>
<td>291 (36)</td>
<td>74 (9)</td>
<td>302 (37)</td>
<td>151 (18)</td>
</tr>
<tr>
<td>40. Using a bank or post office account</td>
<td>815 (100)</td>
<td>101 (12)</td>
<td>25 (3)</td>
<td>278 (34)</td>
<td>411 (50)</td>
</tr>
<tr>
<td>41. Shopping or doing errands</td>
<td>812 (99)</td>
<td>300 (37)</td>
<td>88 (11)</td>
<td>307 (38)</td>
<td>117 (14)</td>
</tr>
<tr>
<td>43. Taking responsibility for him/herself</td>
<td>810 (99)</td>
<td>626 (77)</td>
<td>127 (16)</td>
<td>43 (5)</td>
<td>14 (2)</td>
</tr>
<tr>
<td>44. Supporting family members as needed</td>
<td>815 (100)</td>
<td>513 (63)</td>
<td>87 (11)</td>
<td>177 (22)</td>
<td>38 (5)</td>
</tr>
<tr>
<td><strong>Relationships</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45. Maintaining a loving relationship with parents</td>
<td>814 (100)</td>
<td>760 (93)</td>
<td>45 (6)</td>
<td>8 (1)</td>
<td>1 (0)</td>
</tr>
<tr>
<td>46. Maintaining a loving relationship with other members of family living at home</td>
<td>815 (100)</td>
<td>635 (78)</td>
<td>57 (7)</td>
<td>7 (1)</td>
<td>116 (14)</td>
</tr>
<tr>
<td>47. Maintaining a loving or social relationship with other relatives</td>
<td>811 (99)</td>
<td>729 (89)</td>
<td>45 (6)</td>
<td>17 (2)</td>
<td>20 (2)</td>
</tr>
<tr>
<td>48. Maintaining friendly links with other young people at school or at leisure</td>
<td>810 (99)</td>
<td>626 (77)</td>
<td>127 (16)</td>
<td>43 (5)</td>
<td>14 (2)</td>
</tr>
<tr>
<td>49. Maintaining friendly links with other adults</td>
<td>813 (99)</td>
<td>719 (88)</td>
<td>71 (9)</td>
<td>19 (2)</td>
<td>4 (0)</td>
</tr>
<tr>
<td><strong>School</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Getting to school, entering and moving about within the school and yard*</td>
<td>804 (98)</td>
<td>539 (66)</td>
<td>265 (32)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>14. Taking part in lessons, assignments and assessments at school*</td>
<td>801 (98)</td>
<td>434 (53)</td>
<td>367 (45)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Arch Phys Med Rehabil Vol 93, December 2012
PARTICIPATION AND ENVIRONMENT IN CEREBRAL PALSY, Colver

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.

Acknowledgments: We thank the study’s research associates—Kerry Anderson, BSc, Barbara Caravale, MD, Malin Carlsson, MD, Eva Lise Eriksen, BSc, PhD, Delphine Fenieys, PhD, Bettina Gehring, MD, Louise Gibson, MD, Heidi Kiecksee, BSc, Ann Madden, BSc, and Ondine Pez, PhD—for their enthusiasm and dedication in contacting families and collecting high quality data.

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

<table>
<thead>
<tr>
<th>Assessment of Life Habits Domains and Items</th>
<th>No. (% of Respondents)</th>
<th>Without Difficulty (coded as 0)</th>
<th>With Difficulty (coded as 1)</th>
<th>Too Difficult (coded as 2)</th>
<th>Other Reasons (coded as missing)</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Using school facilities*</td>
<td>796 (97)</td>
<td>518 (63)</td>
<td>278 (34)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>52. Taking part in a range of extra classes including physical education, music, etc</td>
<td>755 (92)</td>
<td>270 (33)</td>
<td>144 (18)</td>
<td>154 (19)</td>
<td>187 (23)</td>
</tr>
<tr>
<td>53. Doing homework</td>
<td>807 (99)</td>
<td>296 (36)</td>
<td>285 (35)</td>
<td>75 (9)</td>
<td>152 (19)</td>
</tr>
<tr>
<td>54. Taking part in activities organized by the school</td>
<td>806 (99)</td>
<td>517 (63)</td>
<td>252 (31)</td>
<td>15 (2)</td>
<td>22 (3)</td>
</tr>
</tbody>
</table>

| 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 (11)                     | 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.

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.

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

<table>
<thead>
<tr>
<th>Participation Domain (Life-H)</th>
<th>Environmental Domain (ECEQ)</th>
<th>Standardized Regression Coefficients Relating Participation to:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Environment</td>
<td>Impairment (b (95% CI)* P)</td>
</tr>
<tr>
<td>Mealtimes</td>
<td>Physical environment: home</td>
<td>0.22 (0.12 to 0.32) 0.001</td>
</tr>
<tr>
<td>Health hygiene</td>
<td>Physical environment: home</td>
<td>0.22 (0.05 to 0.38) 0.011</td>
</tr>
<tr>
<td>Personal care</td>
<td>Physical environment: home</td>
<td>0.32 (0.22 to 0.43) &lt;0.001</td>
</tr>
<tr>
<td>Home life</td>
<td>Physical environment: home</td>
<td>0.30 (0.19 to 0.41) &lt;0.001</td>
</tr>
<tr>
<td>Mobility Transport</td>
<td>Physical environment: home</td>
<td>0.52 (0.27 to 0.76) &lt;0.001</td>
</tr>
<tr>
<td>Mobility Community</td>
<td>Physical environment: community</td>
<td>0.51 (0.29 to 0.74) &lt;0.001</td>
</tr>
</tbody>
</table>

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.

1Percent change in variance between models with and without ECEQ domain, constraining Life-H measurement model without ECEQ to be identical to model with ECEQ.
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

<table>
<thead>
<tr>
<th>Participation Domain (Life-H)</th>
<th>Environmental Domain (ECEQ)</th>
<th>b* (95% CI)</th>
<th>P</th>
<th>RMSEA</th>
<th>CFI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responsibilities</td>
<td>Physical environment: home</td>
<td>0.20 (0.11 to 0.28)</td>
<td>&lt;0.001</td>
<td>0.050</td>
<td>0.991</td>
</tr>
<tr>
<td>Atitudes: family and friends</td>
<td>0.13 (0.06 to 0.19)</td>
<td>&lt;0.001</td>
<td>0.044</td>
<td>0.991</td>
<td></td>
</tr>
<tr>
<td>Atitudes: teachers and therapists</td>
<td>0.06 (-0.01 to 0.12)</td>
<td>0.122</td>
<td>0.056</td>
<td>0.985</td>
<td></td>
</tr>
<tr>
<td>Atitudes: classmates</td>
<td>0.09 (0.02 to 0.16)</td>
<td>0.008</td>
<td>0.060</td>
<td>0.988</td>
<td></td>
</tr>
<tr>
<td>Social support: home</td>
<td>0.35 (0.19 to 0.50)</td>
<td>&lt;0.001</td>
<td>0.042</td>
<td>0.993</td>
<td></td>
</tr>
<tr>
<td>Social support: community</td>
<td>0.18 (0.07 to 0.29)</td>
<td>0.001</td>
<td>0.064</td>
<td>0.976</td>
<td></td>
</tr>
<tr>
<td>Relations</td>
<td>Attitudes: family and friends</td>
<td>0.22 (0.10 to 0.33)</td>
<td>&lt;0.001</td>
<td>0.037</td>
<td>0.989</td>
</tr>
<tr>
<td>Atitudes: teachers and therapists</td>
<td>0.08 (-0.04 to 0.19)</td>
<td>0.185</td>
<td>0.047</td>
<td>0.981</td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>Physical environment: school</td>
<td>0.19 (-0.07 to 0.44)</td>
<td>0.148</td>
<td>0.072</td>
<td>0.964</td>
</tr>
<tr>
<td>Attitudes: teachers and therapists</td>
<td>0.32 (0.23 to 0.41)</td>
<td>&lt;0.001</td>
<td>0.063</td>
<td>0.961</td>
<td></td>
</tr>
<tr>
<td>Atitudes: classmates</td>
<td>0.12 (0.02 to 0.22)</td>
<td>0.020</td>
<td>0.076</td>
<td>0.964</td>
<td></td>
</tr>
<tr>
<td>Social support: home</td>
<td>0.35 (0.20 to 0.50)</td>
<td>&lt;0.001</td>
<td>0.045</td>
<td>0.987</td>
<td></td>
</tr>
<tr>
<td>Social support: community</td>
<td>0.30 (0.19 to 0.41)</td>
<td>&lt;0.001</td>
<td>0.064</td>
<td>0.967</td>
<td></td>
</tr>
</tbody>
</table>

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.

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.
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 \( \leq 0.05 \) and the CFI was \( >0.95 \). 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 \( \text{lh}^* \) refers to Assessment of Life Habits items and eceq* refers to ECEQ items.

Model of health hygiene \( \times \) physical environment home: \( \text{lh}2 \) (getting in and out of bed) was correlated with walking ability;

Model of personal care \( \times \) physical environment home: \( \text{lh}6 \) (dressing and undressing upper half of body) was correlated with \( \text{lh}7 \) (dressing and undressing lower half of body);

Model of home life \( \times \) physical environment home: \( \text{lh}10 \) (entering and leaving home) was correlated with \( \text{lh}11 \) (moving around the home) and \( \text{lh}34 \) (moving about just outside the home).

Model of school \( \times \) attitudes of teachers and therapists: \( \text{lh}52 \), \( \text{lh}53 \), eceq30 (teachers/doctors listen to your views), eceq46 (child has school placement s/he needs) were correlated with the latent factor for impairment.

### References


