



# How does the environmental inadequacy mediate the effect of functional limitations on participation restrictions in young adults with cerebral palsy?

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## ARTICLE INFO

### Keywords:

Environment  
Participation  
Cerebral palsy  
Young adults  
Mediating effect

## ABSTRACT

**Background:** Adults with cerebral palsy (CP) face various functional limitations and comorbidities, that prevent them from participating fully in social life. Disability models suggest that an environment not tailored to their needs could partly explain the link between functional limitations and participation restrictions. However, there is still insufficient knowledge about how the environment hinders participation.

**Objective:** To investigate the mediating role of environmental inadequacy in the relationship between functional limitations and participation restrictions in young adults with CP.

**Methods:** Cross-sectional study, which included 310 young adults with CP, aged 22–27 years at interview (2018–2020) and recruited in well-defined geographical areas in France, Germany, Italy, Portugal and Sweden. Environmental inadequacy was assessed using the EAEQ and participation restrictions using the QYPP-YA. A theoretical model was tested with a partial least squares structural equation model.

**Results:** Functional limitations had a significant direct effect on participation restrictions ( $\beta = 0.62$ ,  $p < 0.001$ ). A small part of the total effect was mediated by the “inadequacy of services, systems and policies” environmental latent variable ( $\beta = 0.10$ ,  $p < 0.001$ ). “Inadequacy of support and relationships” and “inadequacy of attitudes” environments demonstrated no mediating effect. Unexpectedly, a higher “inadequacy of products and technology” environmental score appeared to reduce participation restrictions ( $\beta = -0.10$ ,  $p = 0.025$ ).

**Conclusions:** The environment considered as suggested by the ICF had only a minimal mediating effect in our study. However, public health policies must give priority to improvements at the macro-environmental level, particularly in terms of availability and access to the “services, systems and policies”.

## 1. Introduction

Individuals with disability experience more participation restrictions throughout their lives than their counterparts in the general population.<sup>1</sup> This implies limitations in their active involvement in various aspects of daily life and their integration into society, making

participation, for some authors, the “ultimate target for rehabilitation”.<sup>2</sup> Although it is well known that the participation of people with disability decreases with increasing severity of impairment, altered health status may not explain all participation restrictions in this population. As defined by the International Classification of Functioning, Disability and Health (ICF), restrictions in participation result from an imbalance between “body function and structures”, “personal factors” and

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<https://doi.org/10.1016/j.dhjo.2024.101736>

Received 17 May 2024; Received in revised form 6 November 2024; Accepted 11 November 2024

Available online 14 November 2024

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## Abbreviations

BFMF	Bimanual Fine Motor Function
CI95 %	95 % confidence interval
CP	cerebral palsy
EAEQ	European Adult Environment Questionnaire
EDACS	Eating and Drinking Ability Classification System
EFs	environmental factors
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
IQ	intellectual quotient
LVs	latent variables
PLS-SEM	partial least squares structural equation modeling
QYPP-YA	Questionnaire of Young People's Participation – Young Adults
SCPE	Surveillance of Cerebral Palsy in Europe
SPARCLE	Study of PARTICipation of children with Cerebral palsy Living in Europe
SRMSR	standardized root mean square residual
VIF	variance inflation factor
VSS	Viking Speech Scale

“environmental factors” (EFs).<sup>3</sup> EFs are external elements that influence an individual's life and functioning. They include the proximal environment, such as the physical environment, social relationships, and attitudes, as well as the more distant environment, such as societal systems, services, and laws.<sup>3</sup> The ICF model suggests that an inadequate environment could be detrimental to participation.<sup>3</sup> Some studies have even highlighted that an insufficiently adapted environment may play a mediating role in the link between disabilities and participation restrictions in childhood.<sup>4,5</sup> Previous studies in children and adolescents has shown that severe limitations in functioning increase the need for environmental adaptation and an insufficiently adapted environment would not compensate for disabilities and could explain part of the restrictions on participation linked to disability for children and adolescents.<sup>4,5</sup> However, the mediating role of environmental inadequacy in the participation of young adults with disability is still poorly explored by international research, while the environment is notably adaptable, making it an essential subject of study for improving participation.

Among disabilities, cerebral palsy (CP) is of particular scientific interest because of its prevalence (it is the most common early-onset physical disability),<sup>6</sup> the nature and severity of impairments and comorbidities (impaired motor function often accompanied by “disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy, and by secondary musculoskeletal problems”).<sup>7</sup> In addition, people with CP experience a range of participation restrictions, whose description, origins and implications for daily life are well documented in childhood and adolescence.<sup>8,9</sup> However, these findings cannot be generalized to adulthood, as needs and expectations change considerably after the transition to adulthood.<sup>10</sup> In studies that directly question them, adults with CP consider their participation as central to their daily lives, sometimes even as central as their health condition.<sup>11</sup> They also identify key areas that should be addressed, such as employment, accessibility and mobility, independent living in the community and autonomy (including financial autonomy), communication, access to media and assistive technologies, leisure activities, democratic participation and self-determination.<sup>10–12</sup> One participative study had defined an ICF-Core-Set for adults with CP, which includes an environmental classification, structuring the EFs relevant to this population into four chapters, named “products and technology”, “support and relationships”, “attitudes” and “services, systems and policies”. This disability- and age-specific classification aims to reflect adults with CP

actual experience of the environment.<sup>13</sup> Understanding the extent to which inadequacy of these environments is associated with participation restrictions among these young adults will help to identify potential levers for improving their participation.

This study aimed to quantify, using the European Adults Environment Questionnaire (EAEQ), the mediating role of the four environmental chapters of the ICF-Core-Set in the effect of the functional limitations on participation restrictions in young adults with CP.

## 2. Methods

### 2.1. Study design and population

This cross-sectional study, part of the SPARCLE3 program, involved young adults with CP (according to the Surveillance of Cerebral Palsy in Europe (SCPE) definition),<sup>14</sup> born between July 31, 1991 and April 1, 1997, aged 22–27 years at the time of data collection (2018–2020).<sup>15</sup> The study combined longitudinal follow-up of young people with CP of previous SPARCLE waves (identified from population-based registries in Haute-Garonne and Isère counties in France, Viterbo region in Italy, and Goteborg region in Sweden, or from multiple sources in Lübeck region in Germany) and an additional sample with the same eligibility criteria from multiple sources in Lübeck and Porto Metropolitan area (Portugal). In all countries, ethical approvals have been obtained in accordance with institutional and/or national regulations.<sup>15</sup>

### 2.2. Data collection

All data for the SPARCLE3 study were collected through a single questionnaire, completed by the participants themselves. In cases where self-reporting was not possible, a close relative or personal assistant, with knowledge of their daily habits, acted as a proxy. This process was supervised by a trained research associate.

#### 2.2.1. Personal factors

The following personal and sociodemographic characteristics were collected from the participant during the interview: sex (male, female), age at interview, country of residence (France, Germany, Italy, Portugal, Sweden), population size of place of residence (>200,000 inhabitants, 3000–200,000 inhabitants, <3000 inhabitants), perception of income (living comfortably, coping or finding it difficult), lifestyle (independently (with partner, single or separated, in cohabitation), with family member(s), in care facilities), highest level of education (university studies, upper secondary or short cycle tertiary education, primary or lower secondary education), and current activity (employment (paid and unpaid), in education, unemployed/other).

#### 2.2.2. Functional limitations

The following impairment characteristics were collected in a standardized way by research associates, all trained by the same pediatrician: gross motor function according to the Gross Motor Function Classification System (GMFCS) (level I-II-III; level IV-V),<sup>16</sup> fine motor function using the Bimanual Fine Motor Function classification (BFMF) (I-II-III; IV-V),<sup>17</sup> hearing impairment and visual impairment (no, yes),<sup>18</sup> speaking ability using the Viking Speech Scale (VSS) (not affected by motor disorder, imprecise but usually understandable to unfamiliar listeners, unclear and not usually understandable to unfamiliar listeners, no understandable speech),<sup>19</sup> urinary incontinence (no incontinence, slight/moderate, severe/very severe),<sup>20</sup> fecal incontinence (minimal, moderate, severe/major),<sup>21</sup> epilepsy (no epilepsy with or without medication in last year, less than once a month in the last year, more than once a month in the last year), eating and drinking ability using the Eating and Drinking Ability Classification System (EDACS) (high competence, moderate competence, limited competence),<sup>22</sup> intellectual quotient (IQ) (IQ > 70, 50 ≤ IQ ≤ 70, IQ < 50).

### 2.2.3. Environmental inadequacy

The inadequacy of the physical, social and attitudinal environment to individual needs was assessed using the EAEQ.<sup>23</sup> Each questionnaire item refers to a specific EF. Some items first ask individuals about the need of the targeted EF (needed, not needed) and, if needed, its availability in the environment (available, not available). Others items were considered as universal, so that only their availability in the individual's environment were asked. Item responses were categorized in two modalities: unmet need (needed and not available) or met need (either not needed or needed and available). Our previous work structured the items of the EAEQ in 22 categories and 4 chapters, covering 80 % of the environmental classification of the ICF-Core-Set for adults with CP and showed good face validity (see the questionnaire structure in Table 2).<sup>23</sup>

To ensure that the EAEQ items were sufficiently discriminating for the analysis, those with a rare modality (defined as a frequency <5 %) were excluded. For each participant, the level of environmental inadequacy was calculated for each of the 22 categories as the ratio between his/her number of unmet needs in the category and the number of completed items in the category. If the participant had answered less than half of the category items, his/her category score was not calculated.

### 2.2.4. Participation restriction

Participation restrictions were assessed using the Questionnaire of Young People's Participation – Young Adults (QYPP-YA). Initially designed for children and teenagers, the QYPP was adapted during focus groups to meet the needs of adults with CP, and resulted in the QYPP-YA.<sup>24,25</sup> It comprises 22 items for which responses are given on a 5- or 7-point Likert scale, asking directly about either the frequency or the level of participation. Participation was structured in 6 distinct domains (see Table 3): “autonomy”, “intimate relationships”, “interpersonal relationships”, “social life”, “online communications” and “independence”. Each item was rescaled ranging from 0 to 100. Subsequently, for each participant, a domain score was computed by averaging the responses to the items within each domain. In cases where individuals had missing data for over half of the items within a specific domain, the score was not calculated.

## 2.3. Statistical analysis

### 2.3.1. Descriptive results

Personal factors and functioning limitations of the sample were described using frequencies and proportions or mean and SD according to the nature of the variables, with frequencies of missing values presented. Environment and participation data were described through frequencies and proportions. Descriptive analyses were performed with STATA 14.2 (StataCorp, Texas, USA). For all analyses, the significance level was set at 5 %.

### 2.3.2. Partial least squares - structural equation Modeling (PLS-SEM)

The theoretical model presented in Fig. 1 makes it possible to estimate 1) the direct effect of functional limitations on participation restrictions and 2) the specific indirect effects mediated by each environmental latent variables. A Partial Least Squares Structural Equation Modeling (PLS-SEM) methodology was applied to test this theoretical model with SmartPLS software (4.1.0.0).<sup>26</sup> PLS-SEM is a statistical approach which uses latent variables, representing unmeasured concepts, constructed from observed variables (also known as “indicators”). The model in Fig. 1 represents the theoretical paths between 10 latent variables (LVs) constructed from observed variables (i.e. four environmental inadequacy LVs, one functional limitations LV, one participation restrictions LV and three personal factors LVs). The “functional limitations” latent variable was constructed by the referred observed variables as presented in the “Functional limitations” section of the data collection. The “participation restrictions” latent variable was constructed by the 6 domains scores of participation restrictions

**Table 1**

Sociodemographic and functional limitations characteristics of young adults with CP participating in the SPARCLE3 study (N = 310).

Socio-demographic variables		
<b>Age (years)</b>	<i>Mean</i>	<i>SD</i>
Age	24.27	1.6
<b>Sex</b>	<i>N</i>	<i>%</i>
Male	171	55.2 %
Female	139	44.8 %
Missing	.	
<b>Country</b>		
France (Grenoble, Toulouse)	82	26.5 %
Germany (Lübeck)	78	25.2 %
Italy (Viterbo)	23	7.4 %
Portugal (Porto)	98	31.6 %
Sweden (Göteborg)	29	9.4 %
Missing	0	
<b>Population size of place of residence</b>		
>200,000 inhabitants	107	34.7 %
3000–200,000 inhabitants	145	47.1 %
<3000 inhabitants	56	18.2 %
Missing	2	
<b>Perception about income</b>		
Living comfortably with present income	98	32.3 %
Coping with present income	136	44.9 %
Finding it difficult with present income	69	22.8 %
Missing	7	
<b>Lifestyle</b>		
Independently (with partner, single or separated, in cohabitation)	61	19.7 %
With family member(s)	216	69.9 %
In care facilities	32	10.4 %
Missing	1	
<b>Highest level of education</b>		
University studies	16	5.3 %
Upper secondary or short cycle tertiary education	112	36.7 %
Primary or lower secondary education	177	58.0 %
Missing	5	
<b>Current activity</b>		
Employment (paid and unpaid)	84	27.1 %
In education	46	14.8 %
Unemployed/Others	108	58.1 %
Missing	0	
<b>Functional limitations</b>		
<b>Gross motor function (GMFCS)<sup>17</sup></b>		
Type I-II-III	194	62.6 %
Type IV-V	116	37.4 %
Missing	0	
<b>Fine motor function (BFMF)<sup>18</sup></b>		
Type I-II-III	217	70.0 %
Type IV-V	93	30.0 %
Missing	0	
<b>Hearing impairment</b>		
No	290	93.9 %
Yes	19	6.2 %
Missing	1	
<b>Visual impairment</b>		
No	208	67.1 %
Yes	102	32.9 %
Missing	0	
<b>Speaking ability (VSS)<sup>20</sup></b>		
Not affected by motor disorder	161	51.9 %
Imprecise but usually understandable to unfamiliar listeners	44	14.2 %
Unclear and not usually understandable to unfamiliar listeners	34	11.0 %
No understandable speech	71	22.9 %
Missing	0	
<b>Urinary Incontinence<sup>21</sup></b>		
No incontinence	191	62.4 %
Slight/Moderate	40	13.1 %
Severe/Very severe	75	24.2 %
Missing	4	
<b>Fecal Incontinence<sup>22</sup></b>		
Minim	208	69.1 %
Moderate	48	16.0 %
Severe/Major	45	15.0 %

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Table 1 (continued)

Socio-demographic variables		
Missing	9	
Epilepsy		
No epilepsy with or without medication in last year	259	83.8 %
Less than once a month in the last year	21	6.8 %
More than once a month over the last year	29	9.4 %
Missing	1	
Eat and Drink ability (EDACS) <sup>23</sup>		
High Competence	231	74.5 %
Moderate Competence	59	19.0 %
Limited Competence	20	6.5 %
Missing	0	
Intellectual Quotient		
IQ > 70	127	48.5 %
50 ≤ IQ ≤ 70	52	19.9 %
IQ < 50	83	31.7 %
Missing	48	

SPARCLE3: Study of Participation of children with Cerebral palsy Living in Europe – 3rd wave; CP: Cerebral palsy; GMFCS: Gross Motor Function Classification System; BFMF: Bimanual Fine Motor Function; VSS: Viking Speech Scale; EDACS Eating and Drinking Ability Classification System; IQ: Intellectual Quotient.

measure. The four environmental inadequacy latent variables were constructed of the category scores that composed the correspondent chapter. Personal factors latent variables included the “Social characteristic” latent variable, constructed from perception about income, lifestyle, qualification and current activity indicators, and three single-indicator latent variables for age, sex and population size of place of residence. Statistical significance tests of the PLS-SEM results were based on bootstrapped estimations with 5000 replications.

To ensure the validity of the statistical model, two steps were performed. Firstly, we evaluated the measurement models (i.e. the construction of each latent variable with their indicators). All latent variables were defined as formative constructs, with a mode A weighting mode. Some indicators contained missing data, which were handled using a pairwise deletion treatment.<sup>27</sup> In line with the decision process for maintaining or deleting formative indicators in a latent variable proposed by Hair et al., the outer weights significance and outer loadings of the indicators were examined to evaluate convergent validity (Supplementary material S1).<sup>28</sup> Collinearity was assessed through the variance inflation factor (VIF). VIF values of 5 or higher indicate a potential collinearity problem, leading to deletion of the indicator from the measurement model to which it belongs. Secondly, we evaluated the structural models (i.e. the relationship between the latent variables). The coefficient of determination  $R^2$  for each endogenous (i.e. a variable which is explained in the model by at least another one) variable was calculated.  $R^2$  represents the proportion of the variance of an endogenous construct explained by exogenous variables (i.e. variables not explained by any of other variables of the model). The  $R^2$  values were categorized in three levels:  $R^2 = 0.25$  (weak),  $R^2 = 0.50$  (moderate),  $R^2 = 0.75$  (substantial).<sup>29</sup> The model fit was assessed by the standardized root mean square residual (SRMR), for which a value  $< 0.08$  is generally considered as a good model fit. The absence of collinearity between the latent variables was evaluated with the VIF of each latent variable. A VIF value of 5 or higher indicates a potential collinearity problem between latent variables.

Once the model has been validated, we studied the different direct and indirect paths estimated in the model. These effects were presented as path coefficient  $\beta$  and corresponding 95 % confidence interval (CI95 %). Each  $\beta$  path coefficient can be interpreted as the change in the value of an endogenous construct for each standard deviation unit change in a specific predictor construct, while keeping all other predictor constructs constant.<sup>30</sup> Each  $\beta$  path coefficient between two latent variables of the structural model represents a direct effect. Specific indirect effects are the mediated effects of functional limitations on participation. Four specific indirect effect  $\beta$  coefficients were calculated to estimate the

mediating effect of each latent environmental variable. An indirect effect is determined by multiplying the  $\beta$  path coefficient of the direct effect between functional limitations and environmental inadequacy latent variable of interest by the  $\beta$  path coefficient of the direct effect between environmental inadequacy latent variable of interest and participation restriction.<sup>28</sup> The arithmetic calculations for each of the four specific indirect effects can be found in Table 4.

3. Results

3.1. Description of the sample

The sociodemographic characteristics and functional limitations of the 310 young adults included in the study are presented in Table 1. The maximum percentage of missing data was 15.5 % for IQ. Participants’ mean age was 24 years, 55.2 % were male, 58 % had a primary or lower secondary level of education and 5.3 % a university level, while 27.1 % were employed (paid or unpaid) and 14.8 % were still in education. Overall, 37.4 % were unable to walk (GMFCS IV-V) and 31.7 % had an IQ < 50.

3.2. Description of the environment and participation

The responses to EAEQ EFs are shown in Table 2. In the “products and technology” chapter, unmet needs exceeded 20 % for items referring to public places and land development (except for the EFs referring to the adaptation of school or workplace). Less than 5 % of the sample had unmet needs on items referring from immediate family, extended family and friends in the “support and relationships” chapter. In the “attitudes” chapter, unmet needs ranged from 2.6 % for positive attitudes of family and friends to 28.5 % for attitudes of people in public spaces. In the sample, 14.6 % of individuals said they had no access to any of the 5 EFs forming the “information” category (“services, systems and policies” chapter). Seven EFs were removed from further analyses as they were categorized as unmet needs by less than 5 % of the sample.

Participation is described in Table 3. For each item in the “Autonomy” domain, one in 4 participants said they participated “rarely” or “never”, and even one participant in two for the item “Independence in official and professional business”. Moreover, over 75 % of participants reported that they never spent time alone with their partner and had never had sexual intercourse (76.4 % and 78.2 %, respectively). In the “Interpersonal relationship” domain, more than two in three said they “go to friends’ houses to relax together and meet friends” once a month or less (69.2 %). For “social life” domain, less than 20 % of the sample declared that they had rarely or never “enough money for hobbies and social activities”. Over half of the sample reported engaging once a month or less in activities such as shopping for pleasure, going for a meal in cafés or restaurants, meeting friends to round off the day, going to live music events, and going places spontaneously. For each item of the “independence” domain, more than 40 % of the sample said they never participated.

3.3. Evaluation of measurement models and structural model

Evaluation of measurement models and structural model is presented in supplementary material (S2). It resulted in the deletion of 2 indicators (1 indicator of the latent variable “inadequacy of support and relationship” and 1 indicator from the “functional limitations” LV) and showed satisfactory validity.

3.4. Direct path coefficients

The direct path coefficient, presented in Fig. 1, showed a direct positive link between functional limitations and level of participation restrictions ( $\beta = 0.617$ , CI95 % [0.499; 0.789],  $p < 0.001$ ). The beta coefficients for socio-demographic data are not interpreted or shown in



the figure; they are in supplementary material S2. The direct links between functional limitations and each environmental inadequacy latent variables were positive, with significant paths for “inadequacy of products and technology” and “inadequacy of services, systems and policies” ( $\beta = 0.611$ , CI95 % [0.464; 0.785] and  $\beta = 0.424$ , CI95 %

[0.276; 0.573] respectively,  $p < 0.001$ ) and non-significant paths for “inadequacy of support and relationships” ( $\beta = 0.170$ , CI95 % [0.008; 0.355],  $p = 0.053$ ) and “inadequacy of attitudes” ( $\beta = 0.158$ , CI95 % [-0.049; 0.373],  $p = 0.141$ ). The influence of each environmental inadequacy latent variables on participation restrictions varied in

**Table 2**

Responses to EAEQ items of young adults with CP participating in the SPARCLE3 study (N = 310).

<div>Headings of ICF chapters</div> <div>Headings ICF categories</div> <div>EAEQ questionnaire items</div>	No. (%) of respondents	Met needs	Unmet needs
		n (%)	n (%)
<b>Products and technology</b>			
<b>Design, construction and building products and technology of buildings for private use</b>			
Enlarged rooms or extensions	310 (100)	273 (88.06)	37 (11.94)
Adaptations to the entrance of your home	310 (100)	281 (90.65)	29 (9.35)
Adapted bathroom	310 (100)	259 (83.55)	51 (16.45)
Adaptations to other rooms (e.g. work surfaces in kitchen)	310 (100)	272 (87.74)	38 (12.26)
<b>Products and technology for personal use in daily living</b>			
Aids/adapted equipment for personal care, cooking, housekeeping etc.	309 (99.7)	268 (86.73)	41 (13.27)
<b>Products and technology for communication</b>			
Communication aids at home	310 (100)	293 (94.52)	17 (5.48)
Communication aids at work/college/day placement	306 (98.7)	284 (92.81)	22 (7.19)
<b>Products and technology for education and for employment</b>			
Adapted equipment (e.g. computer)	306 (98.7)	288 (94.12)	18 (5.88)
<b>Products and technology for personal indoor and outdoor mobility and transportation</b>			
Adapted vehicle for getting around	310 (100)	248 (80.00)	62 (20)
<i>Modified wheelchair</i>	310 (100)	296 (95.48)	14 (4.52)
<b>Design, construction and building products and technology of buildings for public use / for culture, recreation and sport</b>			
Adaptations to make all areas at college/work accessible	306 (98.7)	277 (90.52)	29 (9.48)
Adapted toilets at work/college/day placement	306 (98.7)	286 (93.46)	20 (6.54)
Ramps in public places	307 (99.0)	200 (65.15)	107 (34.85)
Adapted toilets or toilet facilities	310 (100)	232 (74.84)	78 (25.16)
Lifts/escalators	310 (100)	242 (78.06)	68 (21.94)
Adapted doorways	310 (100)	238 (76.77)	72 (23.23)
Thinking about the things you like to do outside your home e.g. cinema, doing sport, watching sport, clubs, restaurants - Are the local leisure facilities accessible?	308 (99.4)	234 (75.97)	74 (24.03)
<b>Products and technology of land development</b>			
Accessible pavements in your town or village center	309 (99.7)	208 (67.31)	101 (32.69)
Are public places accessible for you to move around?	308 (99.4)	216 (70.13)	92 (29.87)
<b>Support and relationships</b>			
<b>Acquaintances, peers, colleagues, neighbors and community members / Personal care providers and personal assistants / Health professionals</b>			
Extra time to do what you need to do	306 (98.7)	280 (91.5)	26 (8.5)
<i>Do people around you (personal assistant/students/colleagues/healthcare professionals) help you to do things at work/college/day placement?</i>	309 (99.7)	298 (96.44)	11 (3.56)
<b>Immediate family, extended family, friends</b>			
<i>Help from family and friends to get around</i>	309 (99.7)	307 (99.35)	2 (0.65)
<i>Do family and friends help you to do things at home?</i>	309 (99.7)	301 (97.41)	8 (2.59)
<i>Do you get emotional support from family and friends?</i>	309 (99.7)	299 (96.76)	10 (3.24)
<b>Personal care providers and personal assistants</b>			
A personal assistant to help you at home	310 (100)	262 (84.52)	48 (15.48)
A personal assistant to help you at work/college/day placement	307 (99.0)	287 (93.49)	20 (6.51)
<b>Strangers</b>			
Do people in public places help you to do things?	310 (100)	273 (88.06)	37 (11.94)
<b>Attitudes</b>			
<b>Individual attitudes of acquaintances, peers, colleagues, neighbors and community members / of health professionals</b>			
Teachers, therapists and doctors who listen to your views	306 (98.7)	264 (86.27)	42 (13.73)
<i>Do students/colleagues/healthcare professionals have a positive attitude towards you?</i>	308 (99.4)	293 (95.13)	15 (4.87)
Do staff at college/placement/work understand your needs (medical condition)?	297 (95.8)	259 (87.21)	38 (12.79)
<b>Individual attitudes of immediate family members / of extended family members / of friends</b>			
<i>Do family and friends have a positive attitude towards you?</i>	310 (100)	302 (97.42)	8 (2.58)
Do your family and friends encourage you to do things and to try things out?	308 (99.4)	282 (91.56)	26 (8.44)

<b>Individual attitudes of strangers</b>			
Do the general public/strangers have a positive attitude towards you?	305 (98.4)	218 (71.48)	87 (28.52)
<b>Services, systems and policies</b>			
<b>Social security services, systems and policies</b>			
Financial support/grants from the government/council for: Equipment such as wheelchairs, communication aids, hoists, bathing aids etc.	310 (100)	272 (87.74%)	38 (12.26%)
Financial support/grants from the government/council for: Home modifications	310 (100)	244 (78.71%)	66 (21.29%)
Financial support/grants from the government/council for: A personal assistant	310 (100)	263 (84.84%)	47 (15.16%)
Financial support/grants from the government/council for: Travel/transport	310 (100)	231 (74.52%)	79 (25.48%)
Financial support/grants from the government/council for: Leisure activities/holidays	309 (99.7)	214 (69.26%)	95 (30.74%)
<b>Associations and organizational services, systems and policies</b>			
Support groups in your area	307 (99.0)	250 (81.43%)	57 (18.57%)
<b>General social support services, systems and policies</b>			
Counseling services	308 (99.4)	253 (82.14%)	55 (17.86%)
<b>Health services, systems and policies</b>			
Specialized therapy services, such as: Physiotherapy	309 (99.7)	255 (82.52%)	54 (17.48%)
Specialized therapy services, such as: Speech therapy	309 (99.7)	257 (83.17%)	52 (16.83%)
Specialized therapy services, such as: Occupational therapy	308 (99.4)	256 (83.12%)	52 (16.88%)
Specialized therapy services, such as: A specialist doctor who knows about your condition	310 (100)	275 (88.71%)	35 (11.29%)
<b>Communication services, systems and policies</b>			
Do you have access to social media? (e.g. texting, FB, Twitter)	308 (99.4)	218 (70.78%)	90 (29.22%)
Is information about services easy to understand?	308 (99.4)	186 (60.39%)	122 (39.61%)
Is information about activities in your area, e.g. cinema, easy to understand?	307 (99.0)	222 (72.31%)	85 (27.69%)
Is there information about accessibility of places in your area?	300 (96.8)	140 (46.67%)	160 (53.33%)
Is information about employment/education available to you?	296 (95.5)	155 (52.36%)	141 (47.64%)
<b>Open space planning services, systems and policies</b>			
Accessible car parking in places where you need to park	309 (99.7)	226 (73.14%)	83 (26.86%)
<b>Transportation services, systems and policies</b>			
Adequate public transport (buses/trains/taxis)	309 (99.7)	251 (81.23%)	58 (18.77%)
Accessible public transport (buses/trains/taxis)	308 (99.4)	246 (79.87%)	62 (20.13%)
<b>Civil protection services, systems and policies</b>			
Is public transport safe?	305 (99.4)	208 (68.20%)	97 (31.80%)
Is your local area safe?	308 (99.4)	283 (91.88%)	25 (8.12%)
<b>Education and training services, systems and policies</b>			
Does your college/employer/day placement provide for your needs?	297 (95.8)	238 (80.13%)	59 (19.87%)

Items in italics are those with a rare modality and are removed from the calculations by sub-domain.

EAEQ: European Adult Environment Questionnaire; SPARCLE3: Study of PARTICipation of children with Cerebral palsy Living in Europe – 3rd wave; CP: Cerebral palsy; ICF: International Classification of Functioning, Disability and Health; No: Number; FB: Facebook.

direction and strength. Higher inadequacy in “services, systems and policies” environment significantly increased participation restrictions ( $\beta = 0.224$ , CI95 % [0.095; 0.344],  $p < 0.001$ ). For the “inadequacy of support and relationships” and “inadequacy of attitudes” latent variables, weak and non-significant positive links were observed ( $\beta = 0.014$ , CI95 % [−0.081; 0.099],  $p = 0.764$ , and  $\beta = 0.030$ , CI95 % [−0.052; 0.110],  $p = 0.458$ , respectively). Lastly, a significant negative link was observed for the path between the “inadequacy of products and technology” latent variable and participation restrictions ( $\beta = -0.171$ , CI95 % [−0.302; −0.069],  $p = 0.004$ ), indicating that the more inadequate the environment, the less participation restriction individuals faced.

### 3.5. Specific indirect effect

Specific indirect effects were presented in Table 4. The specific indirect effects of the functional limitations on participation restrictions through “inadequacy of support and relationships” and “inadequacy of attitudes” were not significant ( $\beta = 0.002$ , CI95 % [−0.020; 0.018],  $p = 0.798$ , and  $\beta = 0.005$ , CI95 % [−0.012; 0.021],  $p = 0.551$ , respectively). For the two other indirect specific effects, path coefficients were significant. The specific indirect effect through “inadequacy of products and technology” was negative ( $\beta = -0.104$ , CI95 % [−0.222; −0.037],  $p = 0.025$ ), while that through “inadequacy of services, systems and policies” was positive ( $\beta = 0.095$ , CI95 % [0.042; 0.152],  $p = 0.001$ ).

## 4. Discussion

This study aimed to assess the mediating role of environmental inadequacy in the relationship between functional limitations and participation restrictions faced by young adults with CP. In our analysis, specific indirect effects of the environments were small, and significant only for two chapters. The largest mediating effect was observed for “inadequacy of services, systems and policies”, while no significant effect was found for the “inadequacy of support and relationships” and “inadequacy of attitudes” environmental latent variables. Lastly, the mediating effect of the “inadequacy of products and technology” latent variable showed an opposite effect to those of the others. This means that although functional limitations increased the inadequacy of the “products and technology” environment, the higher levels of inadequacy appeared to reduce participation restrictions.

To our knowledge, no study has previously explored the mediating effect of environmental inadequacies on participation restrictions in young adults with CP or disabilities more generally. However, in children with disability, Anaby et al. highlighted the mediating role of the environment between child-related factors (including disability, health status, functional issues, age and income) and participation.<sup>4</sup> Unlike us, the authors approached the environment and participation through life domains (home, school and community), and showed that the “community” domain most strongly mediated the effect of functional limitations on participation. They hypothesized that the “community” domain is the most complex and contain EFs often difficult to control by the individuals. The chapter “services, systems and policies” used in our

**Table 3**

Responses to QYPP-YA items of young adults with CP participating in the SPARCLE3 study (N = 310).

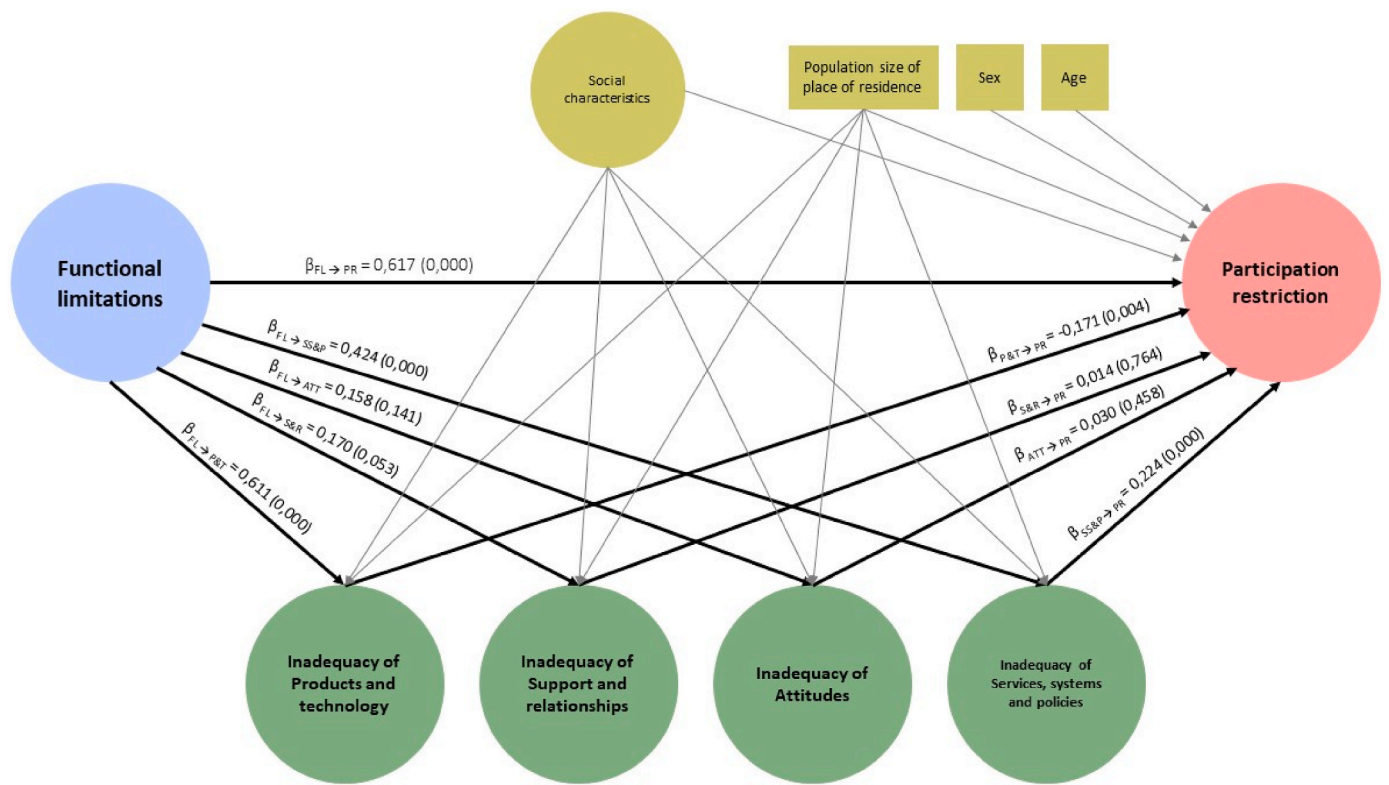
QYPP-YA domain and items	No. (%) of respondents	Response categories n (%)						
<b>Autonomy</b>	<b>No. (%) of respondents</b>	<b>Always or almost always</b>	<b>Most of the time</b>	<b>Some of the time</b>	<b>Rarely</b>	<b>Never</b>		
		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	
At work. appropriate tasks	289 (93.2)	140 (48.4)	61 (21.1)	17 (5.9)	9 (3.1)		62 (21.5)	
Voice in areas of life that are important	304 (98.1)	152 (50.0)	49 (16.1)	28 (9.2)	12 (3.9)		63 (20.7)	
Free time with chosen people	310 (100)	142 (45.8)	51 (16.5)	33 (10.6)	21 (6.8)		63 (20.3)	
Decision in daily routine	310 (100)	118 (38.1)	75 (24.2)	27 (8.7)	27 (8.7)		63 (20.3)	
Independence in official and professional business	310 (100)	70 (22.6)	34 (11.0)	28 (9.0)	10 (3.2)		168 (54.2)	
Decision in spending money	309 (99.7)	141 (45.6)	40 (12.9)	30 (9.7)	19 (6.1)		79 (25.6)	
<b>Intimate relationship</b>	<b>No. (%) of respondents</b>	<b>Every day</b>	<b>About 2 to 6 times a week</b>	<b>About once a week</b>	<b>About 2–3 times each month</b>	<b>About once each month</b>	<b>About once every 2–3 months or less</b>	<b>Never</b>
		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
Spending time with partner without other people	305 (98.4)	30 (9.8)	22 (7.2)	5 (1.6)	6 (2.0)	4 (1.3)	5 (1.6)	233 (76.4)
Sexual contact	303 (97.7)	5 (1.7)	19 (6.3)	9 (3.0)	13 (4.3)	9 (3.0)	11 (3.6)	237 (78.2)
<b>Interpersonal relationship</b>	<b>No. (%) of respondents</b>	<b>Every day</b>	<b>About 2 to 6 times a week</b>	<b>About once a week</b>	<b>About 2–3 times each month</b>	<b>About once each month</b>	<b>About once every 2–3 months or less</b>	<b>Never</b>
		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
Spending time alone with my friends	309 (99.68)	47 (15.2)	66 (21.4)	36 (11.7)	27 (8.7)	17 (5.5)	20 (6.5)	96 (31.1)
Going to friends' houses to relax together and meet friends	309 (99.68)	8 (2.6)	35 (11.3)	22 (7.1)	30 (9.7)	29 (9.4)	48 (15.5)	137 (44.3)
<b>Social life</b>	<b>No. (%) of respondents</b>	<b>Always or almost always</b>	<b>Most of the time</b>	<b>Some of the time</b>	<b>Rarely</b>	<b>Never</b>		
		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	
Enough money to undertake hobbies and social activities	308 (99.35)	142 (46.1)		66 (21.4)	40 (13.0)	18 (5.8)		42 (13.6)
	<b>No. (%) of respondents</b>	<b>Every day</b>	<b>About 2 to 6 times a week</b>	<b>About once a week</b>	<b>About 2–3 times each month</b>	<b>About once each month</b>	<b>About once every 2–3 months or less</b>	<b>Never</b>
		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
Shopping for pleasure	310 (100)	8 (2.6)	18 (5.8)	44 (14.2)	54 (17.4)	49 (15.8)	53 (17.1)	84 (27.1)
Going for a meal in cafés or restaurants	307 (99.03)	4 (1.3)	19 (6.2)	40 (13.0)	78 (25.4)	60 (19.5)	83 (27.0)	23 (7.5)
Meeting friends to round off the day	309 (99.7)	8 (2.6)	28 (9.1)	23 (7.4)	34 (11.0)	32 (10.4)	56 (18.1)	128 (41.4)
Going to live music events	309 (99.7)	1 (0.3)	2 (0.6)	5 (1.6)	19 (6.1)	24 (7.8)	171 (55.3)	87 (28.2)
Going places spontaneously	310 (100)	17 (5.5)	23 (7.4)	30 (9.7)	31 (10.0)	25 (8.1)	23 (7.4)	161 (51.9)
	<b>No. (%) of respondents</b>	<b>About once a month</b>	<b>About once every 2–3 months</b>	<b>About twice a year</b>	<b>About once a year</b>	<b>Every two years</b>	<b>Less than every two years</b>	<b>Never</b>
		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
Going on vacation or weekend trips	310 (100)	28 (9.0)	49 (15.8)	76 (24.5)	65 (21.0)	16 (5.2)	16 (5.2)	60 (19.4)
<b>Online communication</b>	<b>No. (%) of respondents</b>	<b>More than 5 h a day</b>	<b>About 3 to 5 h a day</b>	<b>About 1 to 3 h a day</b>	<b>Every day but less than an hour a day</b>	<b>Several times a week</b>	<b>About 2–3 times a month or less</b>	<b>Never</b>
		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
Going online to connect with different people	310 (100)	40 (12.9)	33 (10.6)	53 (17.1)	42 (13.5)	17 (5.5)	13 (4.2)	112 (36.1)
	<b>No. (%) of respondents</b>	<b>Two times a day or more</b>	<b>About once a day</b>	<b>About 2 to 6 times a week</b>	<b>About once a week</b>	<b>About 2–3 times each month</b>	<b>About once a month or less</b>	<b>Never</b>
		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>

(continued on next page)

Table 3 (continued)

QYPP-YA domain and items	No. (%) of respondents	Response categories n (%)						
Going online to keep up to date with current events	310 (100)	69 (22.3)	56 (18.1)	15 (4.8)	12 (3.9)	7 (2.3)	12 (3.9)	139 (44.8)
Independence	No. (%) of respondents	Completely n (%)		Mostly n (%)	Partly n (%)	Less so n (%)	Not at all n (%)	
Choosing freely profession	304 (98.1)	88 (28.9)		26 (9.0)	34 (11.2)	17 (5.6)	139 (45.7)	
Choosing freely job, apprenticeship, school or internship	305 (98.4)	85 (27.9)		38 (12.5)	32 (10.5)	23 (7.5)	127 (41.6)	
Not having to rely on other people to get from one place to another	310 (100)	90 (29.0)		31 (10.0)	45 (14.5)	11 (3.5)	133 (42.9)	

No: Number; QYPP-YA Questionnaire of Young People's Participation – Young Adults; SPARCLE3: Study of PARTICipation of children with Cerebral palsy Living in Europe – 3rd wave; CP: Cerebral palsy.



**Fig. 1.** Statistical model of the study: Structural model and direct path coefficient  
**Description.** Presentation of the statistical model tested in the analysis using the PLS-SEM methodology. Presentation of the latent variables that constitute the model. Arrows indicate the relationships between the latent variables (represented by a circle). Each arrow was associated with a path coefficient beta and p-value in parentheses.  
P&T: products and technology; S&R: Support and relationships; ATT: Attitudes; SS&P: Services, systems and policies  
Latent variables are represented by circle; Measured variables are represented in squares  
The parameters shown on the arrows are the path coefficients and in brackets their respective pvalues.  
The indicators forming the latent variable set are not shown in the figure, but are explained in the method section.

study, which was the one with the strongest indirect effect, seems very similar to this “community” domain.

In order to understand the specific indirect effects, interpretation of each of the direct effects that constitute them can be proposed. The direct effect of functional limitations on participation is well known in childhood, and our study confirmed this effect in adulthood.<sup>4,31,32</sup>

The direct effect of EFs on participation restrictions was studied for example in the qualitative study by Hammel et al.<sup>33</sup> which identified EFs that can influence participation of people with disability at individual

(micro), community (mesa) and societal (macro) levels, highlighting the need for interventions beyond immediate rehabilitation. Built environment features and social attitudes were identified as key factors affecting participation. Our study confirms that inadequate “services, systems and policies”, that we considered as a macro-level measurement, significantly increased participation restrictions. Unlike Hammel et al.,<sup>33</sup> in our sample inadequacy in “support and relationships” and “attitudes” had no influence on participation, probably because needs regarding these two chapters were almost universally met.<sup>23</sup> The “products and



**Table 4**

Results of specific indirect effect.

Specific indirect effect of each environmental inadequacy latent variables in the relationship between functional limitations and participation restriction	Arithmetic calculation for each specific indirect effect	Specific indirect effect: Path coefficient (Pvalue)
Functional limitations - > Inadequacy of products and technology - > Participation restrictions	$\beta_{FL \rightarrow P\&T \rightarrow PR} = \beta_{FL \rightarrow P\&T} \times \beta_{P\&T \rightarrow PR}$ $= 0.611 \times -0.171$	-0.104 (0.025)
Functional limitations - > Inadequacy of supports and relationships - > Participation restrictions	$\beta_{FL \rightarrow S\&R \rightarrow PR} = \beta_{FL \rightarrow S\&R} \times \beta_{S\&R \rightarrow PR}$ $= 0.611 \times -0.171$	0.002 (0.798)
Functional limitations - > Inadequacy of attitudes - > Participation restrictions	$\beta_{FL \rightarrow ATT \rightarrow PR} = \beta_{FL \rightarrow ATT} \times \beta_{ATT \rightarrow PR}$ $= 0.611 \times -0.171$	0.005 (0.551)
Functional limitations - > Inadequacy of services, systems and policies - > Participation restrictions	$\beta_{FL \rightarrow SS\&P \rightarrow PR} = \beta_{FL \rightarrow SS\&P} \times \beta_{SS\&P \rightarrow PR}$ $= 0.611 \times -0.171$	0.095 (0.001)

FL: Functional limitations; PR: Participation restrictions; P&T: products and technology; S&R: supports and relationships; ATT: attitudes; SS&P: services, systems and policies.

All betas presented in the column “Arithmetic calculation for each specific indirect effect” are shown in Fig. 1.

technology” chapter showed a counter-intuitive effect, indicating that environmental inadequacy reduces participation restrictions. Indeed, each of environmental categories within the “product and technology” chapter could affect different domains of participation.

Finally, the direct effect of functional limitations on inadequacy of environment was confirmed by previous analyses on the same population,<sup>23</sup> showing that increased functional limitations correlated with higher degree of inadequacy in “products and technology” and “services, systems and policies” chapters. Two studies showed that disability itself has a negative influence on attitudes and social support towards adults with disabilities.<sup>34,35</sup> In our sample, we found no association between functional limitations and inadequacy in either the “support and relationships” or “attitudes” environmental chapters.

The weak environment-mediated effect observed here may have several origins. Firstly, other factors or mechanisms may contribute to mitigating the impact of environmental inadequacy on the participation of people with CP, such as coping strategies, social support or other variables not measured in the study. Hammel et al. pointed out that social support can help people cope with difficult and complex environmental systems.<sup>33</sup> In other words, strong social support can compensate for the other environmental difficulties encountered by people with disabilities and thus reduce participation restrictions. As the need for “support and relationships” and “attitudes” in our sample was mostly met, we can assume that this support helps to compensate for other environmental barriers. Secondly, individuals may be unaware of all their environmental needs, as they continually adapt without imagining possible improvements. Identifying patients’ needs to be done at an early stage, emphasizing the importance of support from healthcare professionals. Clinicians play a crucial role in helping patients recognize and express their needs. Shared educational assessments can help identify environmental needs and explore their availability, ensuring that patients receive the support they need to thrive in inclusive environments. Finally, considering environment, participation and functional limitations as global concepts can mask specific effects linked to both the type of functional limitations and the specific environmental needs associated with it, and also to the domains of participation they may influence. It would be interesting to analyze interactions in more detail, in order to reduce the suppressive effects that may exist between all these relationships.

#### 4.1. Limitations

The study has several limitations that need to be considered. We have chosen to model functional limitations, participation and each chapter of the environment as global constructs. Further analysis may explore other options. In terms of measuring the environmental inadequacy, it is important to note that the identification of “needs” could be influenced by the type and severity of disabilities. This consideration raises questions about the generalizability of the results, as individuals’ needs can vary considerably depending on their specific condition, and influence

their participation in specific ways. In this study participation was assessed through the frequency of participation (being there) and not through the assessment of engagement in participation (involvement while there), or participation satisfaction.<sup>36</sup> The interpretation of the results must take these notions into account. Thus, a low level of participation could be seen as satisfactory by the individual, or on the contrary, a high level of participation as unsatisfactory. Moreover, we must acknowledge that our theoretical model is not fully complete. For example, we did not include personal factors like self-efficacy or personality traits, that could influence some of the relationships between the constructs. Secondly, the adequacy of the environment and its impact on participation may differ from country or region, which was not considered in our study due to the small number of participants in each country. In order to measure the environment and participation as perceived by the young adults, we favored self-reports whenever possible. However, one central objective was to include all young people, regardless of their severity profile. We therefore asked someone who knew the young person with CP very well to complete the questionnaire as a proxy when self-report was not possible. We have therefore used the best available description of participation and environment for our analysis as recommended/as done by other authors.

#### 5. Conclusion

Our study indicates that, when considering environmental inadequacy as defined by the ICF, its mediating effect is weak, but provides important evidence of the importance of “services, systems and policies”, which reflects macro-environmental inadequacy, for participation opportunities. Exploring a more subjective concept than participation, such as quality of life, could provide further valuable insights into the mediating effect of the environment. This shift in perspective may/could help identify environmental targets for improving the lives of young adults with CP.

#### CRedit authorship contribution statement

**Célia Perret:** Writing – original draft, Methodology, Formal analysis, Conceptualization. **Virginie Ehlinger:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Jason Shourick:** Writing – review & editing, Methodology, Formal analysis. **Joaquim J. M. Alvarelhão:** Writing – review & editing. **Kate Himmelmann:** Writing – review & editing, Funding acquisition. **Malika Delobel-Ayoub:** Writing – review & editing, Methodology, Conceptualization. **Nicolas Vidart d’Egurbide Bagazgoitia:** Writing – review & editing, Supervision, Formal analysis, Conceptualization. **Catherine Arnaud:** Writing – review & editing, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization.

## Financial disclosure and conflicts of interest

The authors state that this study was conducted in the absence of any commercial or financial relationship that could be construed as a potential conflict of interest.

## Acknowledgments

The authors thank all participants in the SPARCLE3 study for their contribution. We are grateful to all those involved in the development of the EAEQ questionnaire in Newcastle and Lisbon.

## Source of support

The SPARCLE3 study received support from various sources. The German and French contribution, named TRANS-DISAB, was supported by the Deutsche Forschungsgemeinschaft (DFG) and the French Agence Nationale de la Recherche (ANR) [DFG-ANR N°316684170]. Sweden received funding from The Sunnerdahls Handikappfond, the Swedish state under the agreement between the Swedish government and the country councils, the ALF agreement (ALFGBG-726001), Italy from the Fondazione Carivit, and Portugal from the Federação das Associações Portuguesas de Paralisia Cerebral e Santa Casa da Misericórdia de Lisboa. Newcastle University Institute for Social Renewal supported the development of the EAEQ questionnaire. The funders were not involved in any way in the preparation of this manuscript or the decision to submit it.

In France, the Université Toulouse III - Paul Sabatier supported this work by a doctoral grant to Célia Perret, and the CNSA as part of the IRESP 2020 white call for projects (session 11) (N°BLC20\_222199).

## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2024.101736>.

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