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ORIGINAL RESEARCH

Assessing the Adequacy of the Physical, Social, and Attitudinal Environment to the Specific Needs of Young Adults With Cerebral Palsy: The European Adult Environment Questionnaire

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Abstract

Objectives: To present the development of the European Adult Environment Questionnaire (EAEQ), to assess to what extent it covers the International Classification of Functioning, Disability and Health (ICF), and to describe the adequacy of the physical, social, and attitudinal environment to the specific needs of young adults with cerebral palsy (CP).

Design: Cross-sectional.

Setting: Administrative regions in France, Germany, Italy, Portugal, and Sweden.

Participants: Young adults with CP (N=357), with varying severity profiles, aged 19-28 years at time of interview (2018-20).

Interventions: Not applicable.

Main Outcome Measure(s): Physical, social, and attitudinal environment unmet needs.

Results: Relevant environmental factors (EFs) for young adults with CP were identified during focus groups in England and Portugal. EFs were mapped to the ICF environmental classification and the EAEQ analytical structure resulted from this linking procedure. It comprised 61 items, linked to 31 ICF environmental classification categories, and covered 4 of its 5 chapters. Content validity assessed with the bandwidth index (percentage coverage of ICF Core Sets for adults with CP) was satisfactory (79.3%). A descriptive analysis was carried out. Participants had a mean age of 24 years, 56% were men, 38% had severely limited mobility. Less than 16% reported unmet needs for EFs relating to home, college/work/day placement, and communication in the Products and technology chapter. Unmet needs were higher (>20%) for the other items in the Public use and Land development categories. Social support, attitudes, and understanding of relatives were often adequate to the participants' needs. The proportion of unmet needs varied by sex (women were more often concerned) and raised with increasing gross motor impairment.

Conclusion: The EAEQ describes in detail the adequacy of the environment to the specific needs of young adults with CP. Its ICF-based structure opens up possibilities for use in a universal conceptual framework.

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The publication of the International Classification of Functioning, Disability and Health (ICF)[1] in 2001 by the World Health Organization has markedly modified the definition of disability, integrating the environment as an integral part of the conceptual model of health. Disability now refers to the negative aspects of the interaction between individuals with health problems, their personal factors, and the environment. The environment is made up of environmental factors (EFs), which "make up the physical, social, and attitudinal environment in which people live and conduct their lives" and are identified as having an influence, positive or negative, on daily lives.[2] Despite this recognition, scientific research has mainly focused on the study of participation,[3] and the identification of its environmental barriers or facilitators.[4,5] Evidence is still lacking on how to achieve a comprehensive measure of the environment as a stand-alone concept.

Several methods have been used to characterize the environment.[6] In clinical studies, the focus was made on targeted and independent components, to assess the effect of environmental interventions on daily life.[6] Multi-item questionnaires, which study either specific (physical environment, mobility, etc)[7-10] or multiple components of the environment, are favored in observational studies. Many of these studies assess the interaction between the environment and activities of daily living, participation in the society or quality of life, to determine the extent to which the environment acts as an obstacle or a facilitator.[11-18] Some questionnaires contain objective measures about the presence or absence of certain EFs.[19-21] In contrast, subjective description of the environment is achieved by asking individuals about their need for EFs in addition to information about their availability.[12]

Environmental questionnaires can also be generic[17] or conversely, specific to a population. Although the ICF claims to be universally applicable, the environmental needs of people with disabilities are far from those of the general population. A number of disability-specific and/or age-specific ICF core sets have therefore been developed in recent years, to target relevant ICF domains specific to these population.[22] In 2022, Noten et al[23] proposed a specific ICF Core Set for adults with cerebral palsy (CP), as their environmental needs highly depend on the severity of their impairments and co-morbidities, as well as their personal aspirations.

Since 2003, and through 3 follow-up waves, the "Study of PARticipation of children with Cerebral palsy Living in Europe" (SPARCLE) research program has aimed to explore the effect of the environment on participation and quality of life of children (SPARCLE1),[24] adolescents (SPARCLE2),[25] and young adults (SPARCLE3)[26] with CP living in Europe. An integral part of the research was the development of a tool for measuring the adequacy of the proximal environment to the individual needs of the target population as a stand-alone concept and in its diversity. The European Child Environment Questionnaire (ECEQ) was developed in the first wave, and subsequently adapted for adolescents,[27-30] and finally for young adults with the development of the European Adult Environment Questionnaire (EAEQ). Our adaptations through the 3 waves aimed to maintain continuity in the way the environment was measured, and not necessarily in the content of the questions, adapted to each target age.

The aims of the present study were (a) to report on the development of the EAEQ, (b) to assess the extent to which this questionnaire covers the ICF environmental classification and more specifically the ICF Core Set for adults with CP, and report on the analytical structuration of the questionnaire, and (c) to describe the adequacy of the physical, social, and attitudinal environment to the specific needs of young adults with CP using data collected in SPARCLE3.

List of abbreviations:

CP	**cerebral palsy**
EAEQ	**European Adult Environment Questionnaire**
ECEQ	**European Child Environment Questionnaire**
EF	**environmental factor**
ICF	**International Classification of Functioning, Disability and Health**
SPARCLE	**Study of PARticipation of children with Cerebral palsy Living in Europe**

Methods

Development of the EAEQ

The concepts to be considered and the elements to be collected were identified on the basis of the ECEQ and on a literature review.[30] Semi-structured audio-recorded individual and group interviews were conducted with a convenience sample of young adults with CP, representing different levels of functioning and speech production, aged 19-30 years in the North of England (UK) (6 men, 6 women) and in Porto (Portugal) (5 men, 8 women). They were invited to participate through adverts distributed by college/rehabilitation staff and via newsletters of local support organizations. A face-to-face invitation was realized to provide to participants information about the study objectives and procedures (ie, to speak about the features of the environment in which they lived and studies/work that affected their daily lives, in order to develop a new tool to collect information in research). Face-to-face invitation and interviews were conducted by researchers who were experienced in qualitative studies among individuals with CP, and interviewing young people with communication difficulties and intellectual disabilities (LP (PhD) and Janice McLaughlin (PhD) at Newcastle University and a residential further education college (UK), and JA (PhD) and Diana Brandão (PhD) in Cerebral Palsy Rehabilitation Centre of Porto (Portugal)). They had no prior contact with the participants. During interviews, which lasted between 60 and 90 minutes, participant were asked to describe their home and who they lived with; their community; their studies or employment; their leisure activities; their methods of transport and the technology used to keep in touch with others and find information. We asked about who young people interacted with and what affected how frequently and easily they performed activities in the different environments. At each location, 1 researcher led the interviews, the second took field notes. Personal assistants accompanied the young adults. After transcribing the interviews, content analysis and coding were carried out by 2 researchers independently. The researchers then met online to consider the coding across the 2 locations and agreed an initial set of items. Respondents' understanding of the items was assessed through cognitive interviews and focus groups. The questionnaire was structured by life domains to follow a logical flow during administration (supplemental table S1).

ICF-based linking procedure, analytical structure, and content examination

The content of the EAEQ was linked to the ICF environmental classification using the established ICF linking rules.[31,32] Two

assessors (J.A., C.P.) independently identified the meaningful concept(s) per EAEQ item and matched each meaningful concept to the ICF environmental classification category that most accurately represented its content, using the second level of the hierarchy (eg, E115). When an item contained more than 1 meaningful concept, each of them was linked. In case of disagreement between assessors, consensus was reached by discussion. Meaningful concepts that could not be linked were marked as "not covered" by the ICF environmental classification.

The analytical structure of the questionnaire was based on this linkage phase, items grouped by ICF environmental classification category. We considered each category identified as a latent construct. Based on the decision rules proposed in the literature to help identify the measurement model underlying a latent construct,[33] we concluded that items grouped in same construct were not necessarily inter-correlated, but provided information in order to fully define the construct. Thus, formative measurement models were chosen for each EAEQ latent construct. Therefore, the validity analysis was restricted to content validity.

Content density and diversity ratios were calculated to describe the content in relation to the ICF environmental classification. Content density refers to the average number of concepts per item. The higher the value, the greater the number of meaningful concepts per on average. Content diversity ratio corresponds to the number of distinct ICF environmental classification categories in the questionnaire divided by the number of meaningful concepts. A value close to zero indicates that, on average, 1 ICF environmental classification category is covered by several meaningful. The bandwidth index was calculated to assess to what extent the EAEQ covers the ICF environmental classification.[34-36] We considered the 29 distinct categories of the ICF Core Set for adults with CP as denominator for the calculation.[23] Bandwidth corresponds to the percentage of coverage of these ICF Core Set categories by the EAEQ items. The greater the bandwidth, the greater the coverage of the ICF Core Set.

SPARCLE3: study design and population

SPARCLE3 is the third wave of the SPARCLE program. Detailed methods are described elsewhere.[26] In brief, the design combined a longitudinal follow-up of young people with CP who were previously sampled from population-based registries or from multiple sources in European administrative regions (Haute-Garonne and Isère counties in France, Viterbo region in Italy, Goteborg region in Sweden, and Lübeck region in Germany) and who had participated in at least 1 of the 2 first waves of the SPARCLE study, and an additional sample with the same eligibility criteria who had never participated in SPARCLE, recruited from multiple sources in Lübeck and Porto Metropolitan area (Portugal). Because of the exploratory nature of this study, no sample size calculations were made, as data access was dependent on the SPARCLE3 study design, the flowchart of which is shown in figure 1. Individuals with confirmed diagnosis of CP, that is, with an abnormal pattern of movement and posture (spastic, dyskinetic, or ataxic) caused by a non-progressive injury to the immature brain, that may be associated with epilepsy, difficulties of cognition, communication, feeding, vision and hearing, secondary musculoskeletal problems,[37] who were born between 07/31/1991 and 04/01/1997, and aged 22-27 years at the time of data collection (2018-2020) were eligible.

Data collection

The young adults completed standardized home interviews conducted by trained research associates, if necessary with assistance. If not possible, a relative or a personal assistant closely involved in the daily life was interviewed as a proxy.[38]

The following characteristics were collected: sex, age, region of residence, population size of place of residence, walking ability using the Gross Motor Function Classification System,[39] hearing and visual impairment using the Washington Group Short Set on Functioning,[40] speech and communication skills using the Viking

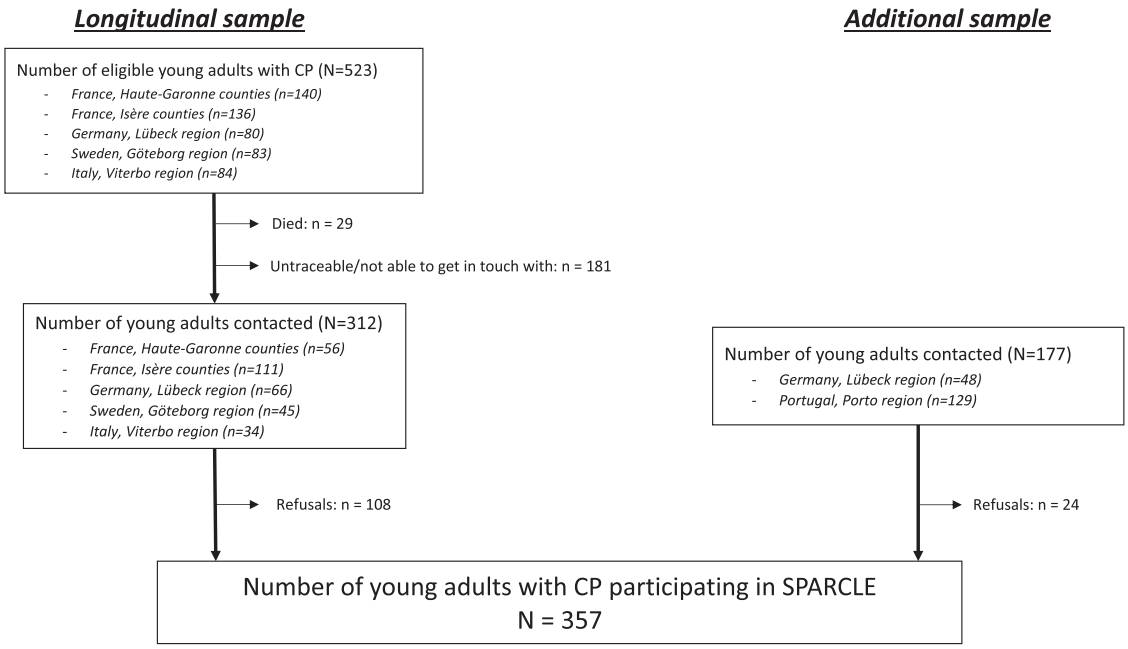

Fig 1 Flow chart of the study. Longitudinal and cross-sectional recruitment process of the 357 young adults of the CP sample of SPARCLE3.

Speech Scale,[41] and the Functional Communication Classification System,[42] respectively. Those instruments are widely used in each country with semantic and conceptual equivalence. They were presented in details in supplemental table S2. The EAEQ contains 2 types of items collecting (1) the need for the EF (Needed/not needed) and, if needed, its availability (Available/not available), or (2) only availability, the need being considered a priori to be common to all individuals. The responses "Needed and not available" reflected an unmet environmental need, while the responses "Not needed" or "Needed and available" were considered to be an environment that meets the need.

Statistical analysis

Descriptive analyses were conducted. Despite some young people were interviewed outside the target age range, they have been retained in the analysis. Sociodemographic, impairments, and EAEQ data were summarized as counts and proportions. For construct of the EAEQ, median, minimum, and maximum percentage of unmet needs were estimated. For each item, proportions of unmet needs for the sample were presented as a whole, by sex, by walking ability, by region, and by population size of place of residence. As missing data were scarce (proportion ranged from 0% (18 items) to 4.0%), no specific statistical methods were used to handle them: the complete dataset was used for all analysis described above. Analyses were performed with STATA 14.2 (StataCorp, Texas, USA).

Results

Development of the EAEQ

Concepts identified as relevant during interviews are listed in table 1. The first version contained 119 items, of which 61 were retained after assessment of item comprehension.

Table 1 Environmental concepts identified as relevant by young adults with CP during focus groups in the developmental phase of the EAEQ

Family, service providers, and public:
- Understanding of needs and positive attitudes
- Communicating using language that is easy to understand
Availability of:
- Appropriate education and employment
- Assistive technology in education
Accessibility of the built environment including streets, buildings, and transport
Adaptation and availability of leisure facilities
Flexibility of personal assistance personnel and consistency and reliability of providers of support
Access to adequate health services
Financial support programs
Access to:
- Internet connection
- Social media

ICF-based linking procedure, analytical structure, and content examination

The 2 assessors identified 79 and 71 meaningful concepts, and linked 73 and 64 of these to the ICF environmental classification, respectively. Forty-four of these linking decisions were common. After consensus, 77 meaningful concepts were retained: 6 were considered "not covered" by the ICF environmental classification, the other 71 were linked to 31 distinct categories of the ICF environmental classification, covering all chapters except chapter 2 "Natural environment and human-made changes to environment". The EAEQ analytical structure is presented in table 2. Content density and content diversity ratios were 1.26 (77/61) and 0.40 (31/77), respectively. In total, 79.3% of the ICF Core Set for adults with CP was covered (bandwidth index: $23/29 \times 100$). Items containing only "not covered" meaningful concepts were classified in an additional category, named "Understand and be understood", which examines whether people in a person's environment understand their way of talking and using language.

Adequacy of the environment, SPARCLE3 study

The sample consisted of 357 young adults with CP, mean age 24 years (SD 2 years), 56% were men and 38.4% were unable to walk (table 3). Overall, 67.1% of participants completed the questionnaire themselves, with or without assistance.

The detailed responses to the EAEQ are described in supplemental table S3 according to ICF environmental classification chapters. Overall, the percentage of individuals reporting an unmet need varied between 0.6% and 53.1% (median: 16%) (fig 2). In the "Products and technology" chapter, the median percentage of participants reporting an unmet need was 12.1%. It varied from 4.2% (item "modified wheelchair") to 35.3% ("ramps in public places"). Unmet needs were more often observed for items of "Design, construction and building products and technology of buildings for public use/for culture, recreation and sport" and "Products and technology of land development" categories. In the "Support and relationships" chapter, unmet needs ranged from 0.6% to 10.2% (median: 5.2%), with higher proportions on items related to "distant" relations that is, strangers in public places, health care professionals, colleagues, and students. A similar pattern was found for the chapters "Attitudes" (median: 9.8%), and "Understand and be understood" (median: 13.5%), with as up to 35.7% of participants reporting a lack of understanding from the general public/strangers of their speech/way of talking. In the "Services, systems and policies" chapter, unmet needs ranged from 9.3% for the safety of the local area to 53.1% for the information about accessibility of places in the area.

Table 4 presents unmet needs according to sociodemographic characteristics and impairment profile. For almost 70% of items (42/61), the proportion of reported unmet needs was higher for women than for men (mean difference 4.9 points, whereas the mean difference for items where men reported unmet needs more frequently than women was 2 points). The "Communication services, systems and policies" category was the 1 with the largest sex differences, with more than 10-point difference for access to information about activities, accessibility of places in the area and employment/education. For 56 items, non-walkers had a higher proportion of unmet needs than walkers, with a particularly marked difference for the "Design, construction and building products and technology of buildings for public use/for culture, recreation and sport" category and the "Products and technology

Table 2 Analytical structure of the EAEQ correspondent to ICF chapter and sub-domain headings, ICF reference codes, and number of elements per chapter and sub-domains

Headings of ICF Chapters and ICF Categories	ICF Code	Number of Items
Products and technology	**Chapter 1**	**19**
Design, construction, and building products and technology of buildings for private use	**E155**	**4**
1. Enlarged rooms or extensions	*E155*	
2. Adaptations to the entrance of your home	*E155*	
3. Adapted bathroom	*E155*	
4. Adaptations to other rooms (eg, work surfaces in kitchen)	*E155*	
Products and technology for personal use in daily living	**E115**	**1**
5. Aids/adapted equipment for personal care, cooking, housekeeping, and etc.	*E115*	
Products and technology for communication	**E125**	**2**
6. Communication aids at home	*E125*	
10. Communication aids at work/college/day placement	*E125*	
Products and technology for education and for employment	**E130/E135**	**1**
9. Adapted equipment (eg, computer)	*E130/E135*	
Products and technology for personal indoor and outdoor mobility and transportation	**E120**	**2**
18. Adapted vehicle for getting around	*E120*	
22. Modified wheelchair	*E120*	
Design, construction, and building products and technology of buildings for public use/for culture, recreation, and sport	**E150/E140**	**7**
7. Adaptations to make all areas at college/work accessible	*E150*	
8. Adapted toilets at work/college/day placement	*E150*	
12. Ramps in public places	*E150*	
13. Adapted toilets or toilet facilities	*E150*	
14. Lifts/escalators	*E150*	
15. Adapted doorways	*E150*	
17. Thinking about the things you like to do outside your home, eg, cinema, doing sport, watching sport, clubs, restaurants - Are the local leisure facilities accessible?	*E150/E140*	
Products and technology of land development	**E160**	**2**
16. Accessible pavements in your town or village center	*E160*	
57. Are public places accessible for you to move around?	*E160*	
Support and relationships	**Chapter 3**	**8**
Acquaintances, peers, colleagues, neighbors, and community members/Personal care providers and personal assistants/Health professionals	**E325/E340/E355**	**2**
11. Extra time to do what you need to do	*E325*	
39. Do people around you (personal assistant/students/colleagues/health care professionals) help you to do things at work/college/day placement?	*E325/E340/E355*	
Immediate family, extended family, friends	**E310/E315/E320**	**3**
23. Help from family and friends to get around	*E310/E315/E320*	
38. Do family and friends help you to do things at home?	*E310/E315/E320*	
44. Do you get emotional support from family and friends?	*E310/E315/E320*	
Personal care providers and personal assistants	**E340**	**2**
31. A personal assistant to help you at home	*E340*	
32. A personal assistant to help you at work/college/day placement	*E340*	
Strangers	**E345**	**1**
40. Do people in public places help you to do things?	*E345*	
Attitudes	**Chapter 4**	**6**
Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members/of health professionals	**E425/E450**	**3**
28. Teachers, therapists, and doctors who listen to your views	*E425/E450*	
42. Do students/colleagues/health care professionals have a positive attitude toward you?	*E425/E450*	
53. Do staff at college/placement/work understand your needs (medical condition)?	*E425*	
Individual attitudes of immediate family members/of extended family members/of friends	**E410/E415/E420**	**2**
41. Do family and friends have a positive attitude toward you?	*E410/E415/E420*	
45. Do your family and friends encourage you to do things and to try things out?	*E410/E415/E420*	

(*continued on next page*)

Table 2 (*Continued*)

Headings of ICF Chapters and ICF Categories	ICF Code	Number of Items
Individual attitudes of strangers	**E445**	**1**
43. Do the general public/strangers have a positive attitude toward you?	*E445*	
Services, systems, and policies	**Chapter 5**	**22**
Social security services, systems, and policies	**E570**	**5**
33. Financial support/grants from the government/council for: Equipment such as wheelchairs, communication aids, hoists, bathing aids, etc.	*E570*	
34. Financial support/grants from the government/council for: Home modifications	*E570*	
35. Financial support/grants from the government/council for: A personal assistant	*E570*	
36. Financial support/grants from the government/council for: Travel/transport	*E570*	
37. Financial support/grants from the government/council for: Leisure activities/holidays	*E570*	
Associations and organizational services, systems, and policies	**E555**	**1**
29. Support groups in your area	*E555*	
General social support services, systems, and policies	**E575**	**1**
30. Counseling services	*E575*	
Health services, systems, and policies	**E580**	**4**
24. Specialized therapy services such as Physiotherapy	*E580*	
25. Specialized therapy services such as Speech therapy	*E580*	
26. Specialized therapy services such as Occupational therapy	*E580*	
27. Specialized therapy services such as A specialist doctor who knows about your condition	*E580*	
Communication services, systems, and policies	**E535**	**5**
46. Do you have access to social media? (eg, texting, FB, Twitter)	*E535*	
58. Is information about services easy to understand?	*E535*	
59. Is information about activities in your area, eg, cinema, easy to understand?	*E535*	
60. Is there information about accessibility of places in your area?	*E535*	
61. Is information about employment/education available to you?	*E535*	
Open space planning services, systems, and policies	**E520**	**1**
19. Accessible car parking in places where you need to park	*E520*	
Transportation services, systems, and policies	**E540**	**2**
20. Adequate public transport (buses/trains/taxis)	*E540*	
21. Accessible public transport (buses/trains/taxis)	*E540*	
Civil protection services, systems, and policies	**E545**	**2**
55. Is public transport safe?	*E545*	
56. Is your local area safe?	*E545*	
Education and training services, systems, and policies	**E585**	**1**
54. Does your college/employer/day placement provide for your needs?	*E585*	
Understand and be understood	**NC**	**6**
47. Do your family and friends understand your speech/way of talking?		
48. Do people around you (personal assistant/students/colleagues/health care professionals) understand your speech/way of talking?		
49. Do the public/strangers understand your speech/way of talking?		
50. Do your family and friends communicate in a way that is easy to understand?		
51. Do people around you (personal assistant/students/colleagues/health care professionals) communicate in a way that is easy to understand?		
52. Do the public/strangers communicate in a way that is easy to understand?		

Abbreviations: FB, Facebook; nc, not covered by ICF.

of land development" category (average difference 31.4 points and 32.7 points, respectively). Conversely, the difference between walkers and non-walkers in the "Attitudes" chapter was small for each item (average difference 3.8 points). We observed the greatest variability between participating countries for the "Public places accessible to move around" item, with French participants declaring 21.8% of unmet needs and Italian participants 62.5%. For more than 50% of the questionnaire items, the frequency of unmet needs was higher for participants living in medium-sized cities (3000 to 200,000 inhabitants) than in other locations.

Discussion

Like the ECEQ, the EAEQ was developed to measure the adequacy of the environment to the individual needs of people with CP. New items identified as relevant to the target age and condition were added in the adult version. The analysis showed a high coverage of the ICF environmental classification, resulting in satisfactory content validity. "Natural environment and human-made changes to environment" was the only chapter of the ICF environmental classification that does not appear in the EAEQ. This

Table 3 Sociodemographic and impairment characteristics of young adults with CP participating in the SPARCLE3 study (N=357)

	n	%
Region		
South West and South East France	88	24.7
North West Germany	110	30.8
Central Italy	24	6.7
Central Portugal	105	29.4
Western Sweden	30	8.4
Sex		
Men	200	56.0
Women	157	44.0
CP subtypes		
Bilateral spastic	196	55.1
Unilateral spastic	94	26.4
Dyskinetic	41	11.5
Ataxic	25	7.0
Missing	*1*	
Population size of place of residence		
<3000 inhabitants	70	19.7
3000–200,000 inhabitants	159	44.8
>200,000 inhabitants	126	35.5
Missing	*2*	
Age (years)	*Mean*	*SD*
	24	2
	Min	*Max*
	19	28
Walking ability (GMFCS[39])		
Level I, II, III: walks, even with limitations	220	61.6
Level IV, V: unable to walk, wheelchair	137	38.4
Hearing impairment		
No	332	93.3
Yes	24	6.7
Missing	*1*	
Visual impairment		
No	243	68.0
Yes	114	32.0
Speaking ability (VSS[41])		
Not affected	189	52.9
Imprecise but usually understandable to unfamiliar listeners	52	14.6
Unclear and not usually understandable to unfamiliar listeners	39	10.9
No understandable speech	77	21.6
Communication ability (FCCS[42])		
Effective communicator in most situations	210	58.8
Effective communicator but does need some help	27	7.6
Effective communicator but small range of messages/topics to most familiar people	26	7.3
Assistance required in most situations	56	15.7
Communicates with others using undirected movement and behavior	38	10.6

Abbreviations: FCCS, Functional Communication Classification System[42]; GMFCS, Gross Motor Function Classification System[39]; SPARCLE3, Study of PARticipation of children with Cerebral palsy Living in Europe – third wave; VSS, Viking Speech Scale.[41]

chapter was also absent from the environmental ICF Core Set for adults with CP.[23] Some categories of the environmental ICF Core Set for adults with CP were also not covered by the EAEQ, partly because they are far removed from everyday concerns such as the attitudes of people in position of authority. Nevertheless, the EAEQ goes beyond the core set by including 8 additional ICF environmental classification categories, allowing a fine-grained description of the environment. If we consider the environment from the perspective of ecological theory,[43-45] the EFs identified in the EAEQ only represent aspects of the environment close to the individual. The ecological model suggests that a more distant environment might also influence lifestyle and activities, but corresponding features did not emerge during the focus groups.

The proportion of unmet needs varied between EAEQ items. Of all the services explored, those related to communication and information matched very poorly the needs. Provision of appropriate information and access to communication technologies have previously been reported to improve the lives of persons with disabilities and to support meaningful inclusion in society.[46,47] Products and technologies for personal indoor and outdoor mobility and transportation, as well as social support from close family and friends, are also vital areas that were identified as facilitating daily lives of individuals with disabilities.[48] They were frequently rated as a met need among SPARCLE3 participants. On the opposite, "Design, construction, and building products and technology of buildings for public use" were identified as significant environmental barriers in the same study[48] and were frequently reported as unmet in our study.

Study limitations

Although our choice was to characterize the environment as a stand-alone concept, we cannot rule out the fact that participants answered the questions thinking about the potential effect of EFs on participation. Nevertheless, our approach has made it possible to limit this effect, with questions formulated to explore the availability of EFs only. Secondly, we defined the environmental construct as formative models. As such, there was no construct validity hypothesis. Comparison of our questionnaire with other tools is limited to content validity, which was satisfactory for the EAEQ.

Because of the limited geographic coverage of the population-based registers on which recruitment was initially based, attrition during follow-up, and the specific additional recruitment in wave 3, the SPARCLE3 sample of young adults with CP is not representative. We have no data at this age to compare the profile of these young people in terms of disability or social characteristics. Nevertheless, we were able to recruit young people with a severe disability profile (38.4% with Gross Motor Function Classification System IV-V), who are very often excluded from the studies.

Implication for practice and research

This questionnaire makes it possible to collect the EFs that are useful to individuals with CP and to analyze whether their availability, modification, or adaptation could improve the achievement

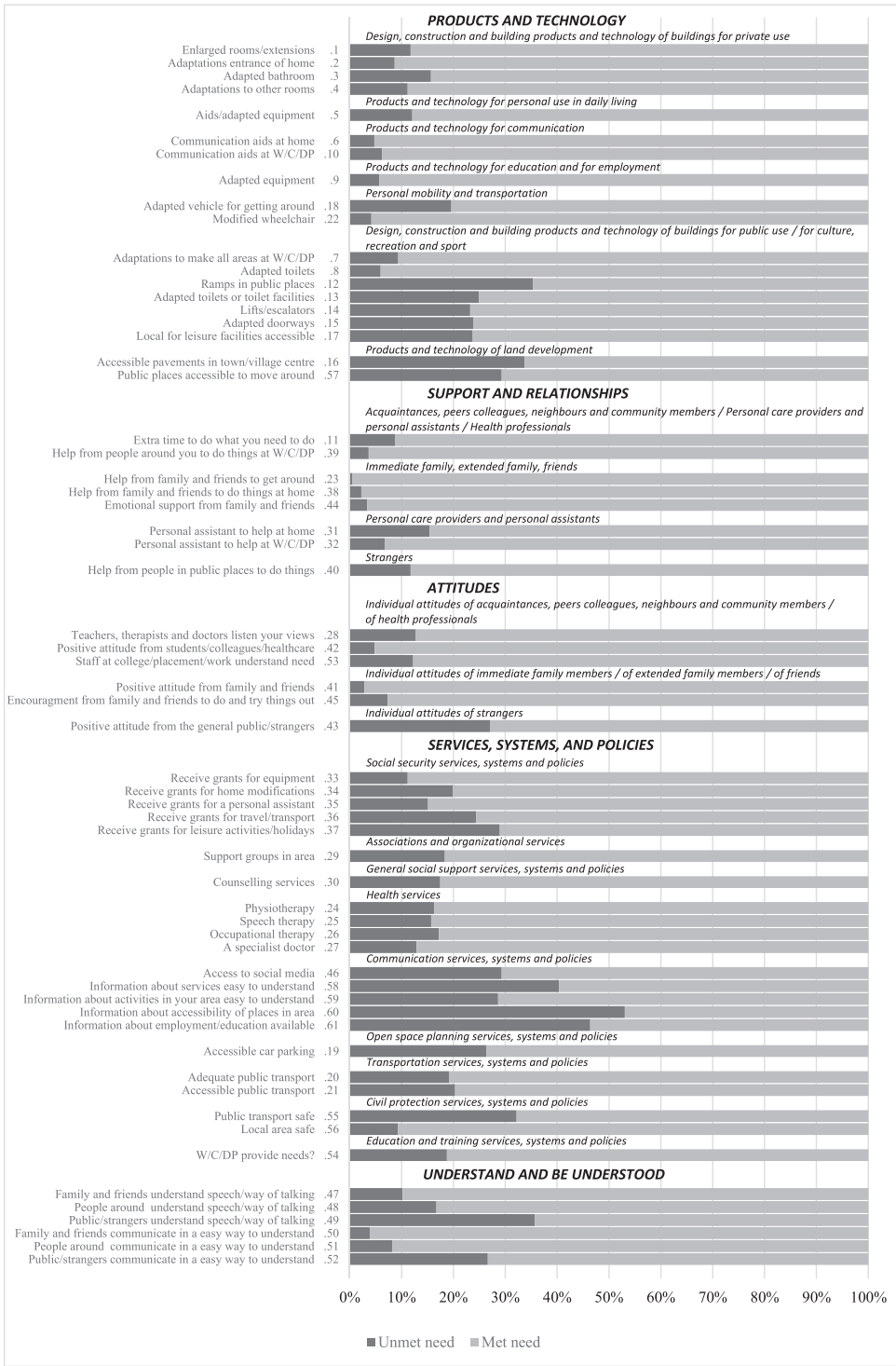

Fig 2 Percentage of unmet and met needs for each of the 61 questionnaire items, structured in its analytical form (ie, based on ICF environmental classification). All percentages are generated on the data available for each item.

of daily activities, participation, and quality of life. Despite the large set of items, which could make the questionnaire tedious to complete, we observed a high response rate on all items (over 96%), that highlight the acceptability of the EAEQ. This suggests the possibility of widespread use in clinical practice. By systematically measuring a wide range of EFs, health care professionals could gain a clear idea of the extent of their patients' needs and help them to make the necessary compensations. Analysis of geographic or temporal differences in the frequency of participation or level of quality of life, coupled with an overall view of unmet environmental needs, could provide the public authorities with the elements for a policy of accessibility and integration of people with disabilities into society. Finally, independent measurement of the environment opens new avenues for studying the associations between environment and a series of patient-reported outcomes.

Table 4 Percentage of young adults with CP participating in the SPARCLE3 study with unmet needs for each EAEQ item, by sex, GMFCS level, region, and population size of place of residence (N=357)

	Unmet Need (%)		Unmet Need (%)		Unmet Need (%)					Unmet Need (%)		
	Sex		GMFCS Level		Region					Population Size of Place of Residence*		
Headings of ICF Chapters and ICF Categories	Male n=200	Female n=157	I, II, III n=220	IV, V n=137	Fr n=88	De n=110	It n=24	Pt n=105	Se n=30	<3000 inhabitants n=70	3000–200,000 inhabitants n=159	>200,000 inhabitants n=126
Products and technology												
Design, construction, and building products and technology of buildings for private use												
1. Enlarged rooms or extensions	9.5	14.6	4.5	23.4	10.2	10.9	12.5	14.3	10.0	4.3	13.8	13.5
2. Adaptations to the entrance of your home	7.0	10.8	4.5	15.3	8.0	6.4	8.3	13.3	3.3	2.9	10.7	9.5
3. Adapted bathroom	14.0	17.8	10.0	24.8	17.0	9.1	33.3	18.1	13.3	7.1	20.1	15.1
4. Adaptations to other rooms (eg, work surfaces in kitchen)	9.5	13.4	5.9	19.7	11.4	5.5	16.7	13.3	20.0	7.1	12.6	11.1
Products and technology for personal use in daily living												
5. Aids/adapted equipment for personal care, cooking, housekeeping, etc.	9.5	15.3	8.2	18.2	13.6	4.5	8.7	20.0	10.0	7.1	15.2	11.1
Products and technology for communication												
6. Communication aids at home	5.0	4.5	1.8	9.5	6.8	0.9	4.2	5.7	10.0	5.7	6.9	1.6
10. Communication aids at work/college/day placement	6.1	6.5	2.7	12.0	8.0	4.7	0.0	6.7	10.7	7.1	8.3	3.2
Products and technology for education and for employment												
9. Adapted equipment (eg, computer)	5.6	5.8	3.2	9.8	5.7	5.6	4.2	4.8	10.7	8.6	7.1	2.4
Products and technology for personal indoor and outdoor mobility and transportation												
18. Adapted vehicle for getting around	16.5	23.6	15.0	27.0	20.5	10.9	33.3	29.5	3.3	11.4	22.6	20.6
22. Modified wheelchair	4.0	4.5	3.6	5.1	2.3	1.8	4.2	9.5	0.0	0.0	6.9	3.2
Design, construction, and building products and technology of buildings for public use/ for culture, recreation, and sport												
7. Adaptations to make all areas at college/work accessible	9.6	9.0	7.8	12.0	8.0	8.4	20.8	8.6	10.7	11.4	12.8	4.0
8. Adapted toilets at work/college/day placement	7.1	4.5	2.3	12.0	4.5	1.9	16.7	7.6	10.7	5.7	9.6	1.6
12. Ramps in public places	31.3	40.4	15.0	68.7	31.8	34.3	37.5	33.7	53.3	32.9	37.6	33.3
13. Adapted toilets or toilet facilities	21.5	29.3	8.6	51.1	12.5	28.2	41.7	21.0	50.0	22.9	26.4	23.8
14. Lifts/escalators	20.5	26.8	8.2	47.4	18.2	30.9	33.3	21.0	10.0	27.1	18.9	26.2
15. Adapted doorways	21.5	26.8	8.2	48.9	25.0	25.5	20.8	20.0	30.0	24.3	21.4	26.2

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Table 4 (*Continued*)

Headings of ICF Chapters and ICF Categories	Unmet Need (%) Sex		Unmet Need (%) GMFCS Level		Unmet Need (%) Region					Unmet Need (%) Population Size of Place of Residence*		
	Male n=200	Female n=157	I, II, III n=220	IV, V n=137	Fr n=88	De n=110	It n=24	Pt n=105	Se n=30	<3000 inhabitants n=70	3000–200,000 inhabitants n=159	>200,000 inhabitants n=126
17. Thinking about the things you like to do outside your home, eg, cinema, doing sport, watching sport, clubs, restaurants - Are the local leisure facilities accessible?	19.1	29.7	12.3	42.2	20.5	24.3	29.2	24.8	23.3	28.6	20.1	25.4
Products and technology of land development												
16. Accessible pavements in your town or village center	31.5	36.5	20.0	55.9	34.1	29.4	54.2	34.3	30.0	30.0	34.6	34.1
57. Are public places accessible for you to move around?	26.1	33.3	17.9	47.4	21.8	24.5	62.5	34.3	24.1	27.1	34.8	23.0
Support and relationships												
Acquaintances, peers colleagues, neighbors, and community members/Personal care providers and personal assistants/Health professionals												
11. Extra time to do what you need to do	9.6	7.7	10.0	6.8	12.5	8.4	4.2	6.7	10.7	10.0	7.1	10.3
39. Do people around you (personal assistant/ students/colleagues/health care professionals) help you to do things at work/college/ placement?	3.5	3.8	4.1	3.0	4.5	4.6	4.2	2.9	0.0	5.7	5.1	0.8
Immediate family, extended family, friends												
23. Help from family and friends to get around	1.0	0.0	0.5	0.7	0.0	0.0	0.0	1.0	3.3	0.0	1.3	0.0
38. Do family and friends help you to do things at home?	2.0	2.6	0.9	4.4	3.4	0.0	0.0	2.9	6.7	2.9	2.5	1.6
44. Do you get emotional support from family and friends?	3.5	3.2	4.1	2.2	0.0	2.8	8.3	5.7	3.3	0.0	4.4	4.0
Personal care providers and personal assistants												
31. A personal assistant to help you at home	14.0	17.2	7.7	27.7	9.1	19.1	4.2	23.8	0.0	14.3	18.9	11.9
32. A personal assistant to help you at work/ college/day placement	6.1	7.7	5.0	9.6	4.6	9.3	8.7	7.6	0.0	10.0	7.7	4.0
Strangers												
40. Do people in public places help you to do things?	13.5	9.6	5.9	21.2	13.6	12.7	20.8	8.6	6.7	17.1	10.7	10.3

(*continued on next page*)

Table 4 (*Continued*)

Headings of ICF Chapters and ICF Categories	Unmet Need (%) Sex		Unmet Need (%) GMFCS Level		Unmet Need (%) Region					Unmet Need (%) Population Size of Place of Residence*		
	Male n=200	Female n=157	I, II, III n=220	IV, V n=137	Fr n=88	De n=110	It n=24	Pt n=105	Se n=30	<3000 inhabitants n=70	3000–200,000 inhabitants n=159	>200,000 inhabitants n=126
Attitudes												
Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members/of health professionals												
28. Teachers, therapists, and doctors who listen to your views	12.7	12.8	12.3	13.4	16.1	10.2	25.0	9.6	13.3	14.3	14.7	9.5
42. Do students/colleagues/health care professionals have a positive attitude toward you?	4.5	5.1	2.3	8.9	5.7	4.6	8.3	2.9	6.7	7.1	5.7	2.4
53. Do staff at college/placement/work understand your needs (medical condition)?	13.0	11.3	9.7	16.5	18.3	9.4	20.8	6.7	18.5	17.1	13.0	7.9
Individual attitudes of immediate family members/of extended family members/of friends												
41. Do family and friends have a positive attitude toward you?	1.5	4.5	1.8	4.4	1.1	1.8	0.0	6.7	0.0	0.0	3.1	4.0
45. Do your family and friends encourage you to do things and to try things out?	6.6	8.3	6.4	8.9	4.5	2.8	8.3	15.2	3.3	5.7	9.5	5.6
Individual attitudes of strangers												
43. Do the general public/strangers have a positive attitude toward you?	28.6	25.3	26.0	28.9	26.7	26.2	0.0	34.3	28.6	30.0	25.9	26.2
Services, systems, and policies												
Social security services, systems, and policies												
33. Financial support/grants from the government/council for: Equipment such as wheelchairs, communication aids, hoists, bathing aids, etc.	9.5	13.4	10.5	12.4	19.3	2.7	8.3	14.3	10.0	10.0	14.5	7.9
34. Financial support/grants from the government/council for: Home modifications	21.0	18.5	11.4	33.6	20.5	11.8	29.2	29.5	6.7	18.6	25.2	14.3
35. Financial support/grants from the government/council for: A personal assistant	11.5	19.7	6.4	29.2	11.4	15.5	8.3	23.8	0.0	14.3	19.5	10.3
36. Financial support/grants from the government/council for: Travel/transport	21.0	28.7	17.3	35.8	29.5	14.5	29.2	34.3	6.7	30.0	25.8	19.8

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Table 4 (*Continued*)

Headings of ICF Chapters and ICF Categories	Unmet Need (%) Sex		Unmet Need (%) GMFCS Level		Unmet Need (%) Region					Unmet Need (%) Population Size of Place of Residence*		
	Male n=200	Female n=157	I, II, III n=220	IV, V n=137	Fr n=88	De n=110	It n=24	Pt n=105	Se n=30	<3000 inhabitants n=70	3000–200,000 inhabitants n=159	>200,000 inhabitants n=126
37. Financial support/grants from the government/council for: Leisure activities/ holidays	25.5	33.3	18.7	45.3	33.3	20.9	33.3	36.2	16.7	25.7	37.1	20.6
Associations and organizational services, systems, and policies												
29. Support groups in your area	20.1	16.1	16.4	21.5	13.6	19.4	34.8	19.0	13.3	18.6	20.9	15.1
General social support services, systems, and policies												
30. Counseling services	17.6	17.3	19.2	14.7	13.8	19.1	30.4	18.1	10.0	14.3	18.9	17.5
Health services, systems, and policies												
24. Specialized therapy services such as: Physiotherapy	18.5	13.5	16.8	15.4	17.0	6.4	29.2	22.9	16.7	12.9	18.2	15.9
25. Specialized therapy services such as: Speech therapy	16.6	14.6	12.3	21.3	14.8	10.1	25.0	21.0	13.3	20.0	18.2	10.3
26. Specialized therapy services such as: Occupational therapy	14.7	20.4	15.1	20.6	18.6	14.7	20.8	22.9	0.0	17.1	17.6	16.7
27. Specialized therapy services such as: A specialist doctor who knows about your condition	12.5	13.4	10.5	16.8	6.8	21.8	20.8	4.8	20.0	14.3	13.8	11.1
Communication services, systems, and policies												
46. Do you have access to social media? (eg, texting, FB, Twitter)	26.1	33.3	17.4	48.5	27.6	32.1	25.0	30.5	23.3	38.6	28.5	25.4
58. Is information about services easy to understand?	38.7	42.6	30.3	56.6	46.6	48.6	41.7	28.6	32.1	45.7	38.9	38.9
59. Is information about activities in your area, eg, cinema, easy to understand?	23.4	35.3	19.7	43.0	36.4	34.9	16.7	22.1	14.3	35.7	27.2	26.2
60. Is there information about accessibility of places in your area?	48.4	58.9	44.2	66.7	42.5	45.6	62.5	64.8	62.5	55.7	57.8	41.3
61. Is information about employment/education available to you?	41.4	52.6	31.8	71.4	46.9	40.9	50.0	51.0	46.2	47.1	50.0	39.7
Open space planning services, systems, and policies												
19. Accessible car parking in places where you need to park	23.6	29.9	15.9	43.4	31.8	21.1	37.5	28.6	13.3	31.4	27.2	23.0

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Table 4 (*Continued*)

Headings of ICF Chapters and ICF Categories	Unmet Need (%) Sex Male n=200	Female n=157	Unmet Need (%) GMFCS Level I, II, III n=220	IV, V n=137	Unmet Need (%) Region Fr n=88	De n=110	It n=24	Pt n=105	Se n=30	Unmet Need (%) Population Size of Place of Residence* <3000 inhabitants n=70	3000–200,000 inhabitants n=159	>200,000 inhabitants n=126
Transportation services, systems, and policies												
20. Adequate public transport (buses/trains/ taxis)	16.6	22.4	12.3	30.1	14.8	17.6	45.8	18.1	20.0	27.1	17.6	15.9
21. Accessible public transport (buses/trains/ taxis)	17.1	24.5	11.0	35.6	18.2	16.8	41.7	19.0	26.7	24.3	20.8	16.7
Civil protection services, systems, and policies												
55. Is public transport safe?	28.2	37.2	22.5	48.1	23.3	32.4	54.2	32.4	39.3	37.1	32.9	27.8
56. Is your local area safe?	9.6	8.9	6.4	14.0	5.7	10.9	12.5	9.5	10.3	8.6	10.2	8.7
Education and training services, systems, and policies												
54. Does your college/employer/day placement provide for your needs?	20.6	16.4	16.7	22.2	20.3	15.0	21.7	20.0	22.2	20.0	20.5	14.3
Understand and be understood												
47. Do your family and friends understand your speech/way of talking?	9.1	11.7	5.5	18.0	11.6	7.5	16.7	12.4	3.3	12.9	8.2	10.3
48. Do people around you (personal assistant/ students/colleagues/ health care professionals) understand your speech/way of talking?	17.2	16.1	7.8	31.3	17.6	16.5	16.7	16.2	16.7	22.9	14.6	15.1
49. Do the public/strangers understand your speech/way of talking?	35.9	35.5	19.7	61.5	30.2	27.8	41.7	42.9	50.0	41.4	35.4	31.7
50. Do your family and friends communicate in a way that is easy to understand?	3.0	5.1	2.3	6.6	1.1	2.7	4.2	6.7	6.9	1.4	4.4	4.8
51. Do people around you (personal assistant/ students/colleagues/health care professionals) communicate in a way that is easy to understand?	7.1	9.6	3.2	16.3	4.5	10.0	4.2	9.6	10.7	12.9	7.0	7.1
52. Do the public/strangers communicate in a way that is easy to understand?	27.8	25.2	17.8	41.0	23.9	31.2	16.7	28.2	20.7	31.4	26.8	23.8

Abbreviations: De, Germany; FB, Facebook; Fr, France; GMFCS, Gross Motor Function Classification System; It, Italy; Pt, Portugal; Se, Sweden; SPARCLE3, Study of PARticipation of children with Cerebral palsy Living in Europe — third wave.

* Two young adults did not fulfil their place of residence.

Conclusion

The EAEQ is an original measurement tool whose use could help accelerate the integration of young adults with CP into society by identifying the environmental changes that would improve their life.

Key Words

Cerebral palsy; Young adults; Environmental questionnaire; Environmental unmet needs; International Classification of Functioning; Disability and Health

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