

Title page

(1) Running head. Environmental factors and cerebral palsy

(2) Title. 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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Highlights

- The EAEQ is a new instrument to describe met and unmet environmental needs
- The EAEQ questionnaire was designed by and for youth with cerebral palsy
- Its structure links fairly well with the ICF Core Set for adults with cerebral palsy
- Environmental needs in the community were poorly met, unlike needs at home/work
- Unmet environmental needs differed by sex, impairment and place of residence

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

Abstract

Objectives: To present the development of the European Adult Environment Questionnaire (EAEQ), to assess to what extent it corresponds to 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: Well-defined geographical areas in France, Germany, Italy, Portugal and Sweden.

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

Interventions: Not applicable.

Main outcome measure(s): Environmental factors (EFs) that were important to improve participation for young adults with CP were identified during focus groups that comprised the target population, families, and health professionals. The EAEQ analytic structure resulted from linkage to the ICF environmental classification.

Results: The EAEQ comprised 61 items, linked to 31 ICF categories, and covering 4 of its 5 environmental chapters. Content validity assessed with the bandwidth index (percentage coverage of ICF Core Sets for adults with CP) was satisfactory (79.3%). Participants in the SPARCLE study 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% of the sample) 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 level of unmet needs varied by sex (women were more often concerned) and increased 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.

List of abbreviations

CHEC Community Health Environment Checklist

CHIEF Craig Hospital Inventory of Environmental Factors

CP Cerebral palsy

EAEQ European Adult Environment Questionnaire

ECEQ European Child Environment Questionnaire

EF Environmental Factors

FABS/M Facilitators And Barriers Survey of environmental influences on participation among people with lower limb Mobility impairments and limitations

GMFCS Gross Motor Function Classification System

HACE Home And Community Environment instrument

ICF International Classification of Functioning, Disability and Health

IDP Interaction with Disabled Persons scale

MAP Measuring Activity and Participation questionnaire

MQE Measure of the Quality of the Environment scale

SPARCLE Study of PARticipation of children with Cerebral palsy Living in Europe

Introduction

Since the publication of the International Classification of Functioning, Disability and Health (ICF)¹ in 2001 by the World Health Organization, the environment has become an integral part of the conceptual model of health. Environmental factors (EFs) “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. Taking the environment into consideration has markedly modified the definition of disability, which now refers to the negative aspects of the interaction between individuals with health problems, their personal factors and the environment.¹ This definition has been adopted by the scientific community, recognizing the theoretical role of EFs in the functioning of people with disabilities.^{2,3} Measuring the environment within the ICF context is now a priority to investigate its empirical role.

This measurement raised many challenges. The first was to consider the scope of environmental features to be covered. The environment as envisaged in the ICF comprises a large set of components which, if measured and used in isolation, could lead to data-dredging.⁴ Researchers then turned to the development of multi-item questionnaires, making it possible to study a wide range of EFs, grouped in such a way as to constitute different environmental domains. However, the main environmental questionnaires developed to date do not fully cover the ICF framework. In some of them, such as the Home And Community Environment instrument (HACE), environmental domains are not constructed on the ICF basis.⁵ Others do not measure all facets of the ICF environmental classification. The Interaction with Disabled Persons scale (IDP) measures attitudes only in terms of discomfort.⁶ The Environmental Analysis of Mobility Questionnaire (EAMQ)⁷ measures only the physical

environmental facets of the ICF, and the Community Health Environment Checklist (CHEC) measures more specifically the home and community physical environment.⁸

The second challenge concerned measurement of the environment as an isolated concept. Because the environment is theoretically linked to activity and participation in the ICF model, many questionnaires measure the interaction between the environment and activity or participation, not just the environment.⁹ For example, the three main environmental multi-item questionnaires developed so far, the Craig Hospital Inventory of Environmental Factors (CHIEF),¹⁰ the Facilitators And Barriers Survey of environmental influences on participation among people with lower limb Mobility impairments and limitations (FABS/M),¹¹ and the Measure of the Quality of the Environment scale (MQE)¹² aim to measure environmental barriers and/or facilitators to participation for people with disabilities. Likewise, the Measuring Activity and Participation questionnaire (MAP)¹³ measures the impact on participation and activities of the absence or presence of a series of EFs.

The third challenge related to the adaptation of the environmental items to the characteristics of the population studied. Although the ICF claims to be universally applicable, the environmental needs of people with disabilities are far from those of the general population, which justifies a disability-specific approach when measuring the environment. The provision of environmental questionnaires adapted to a disabled population, for instance for people with cerebral palsy (CP), is therefore essential. CP is one of the commonest early-onset motor development disorders, with a prevalence of 1.6 per 1000 live births.¹⁴ In addition to limitations of movement and posture control, people with CP have impairments and related conditions of varying severity. For adults with CP, Noten et al¹⁵ proposed in 2022 a selection

of ICF categories from the entire classification, compiled into an ICF Core Set that is specific to this population and is a useful framework on which to base the development of new tools.

As part of the SPARCLE study,¹⁶⁻¹⁸ we developed the European Adult Environment Questionnaire (EAEQ) to measure the adequacy of the environment in its diversity to the needs of young adults with CP. 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 (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 the third wave of the SPARCLE study.

Methods

Development of the EAEQ

Based on reviews of the literature and of other instruments (notably the European Child Environment Questionnaire (ECEQ),¹⁹ which measures the physical, social and attitudinal environment of children with CP, developed in a previous wave of the SPARCLE program),¹⁷ the concepts to be considered and the items to be measured were identified. Semi-structured audio-recorded individual and group interviews were conducted with young adults with CP aged 19-30 years in the North of England (UK) (6 men, 6 women) and in Porto (Portugal) (5 men, 8 women). An initial set of environmental items relevant to facilitating participation in this population was obtained and items were grouped into thematic categories. Respondents' understanding was then assessed through cognitive interviews and focus groups. Some items were dropped during this process. The questionnaire was structured by life domains to follow a logical flow during administration.

ICF-based content examination

Linking procedure. The content of the EAEQ was linked to the ICF environmental classification using the established ICF linking rules.^{20,21} Two assessors (JA, CP) independently identified the meaningful concept(s) per EAEQ item, and carried out the linking procedures, matching each meaningful concept to the ICF category that most accurately represented its content, using the second level of the hierarchy (e.g. E115). When an item contained more than one meaningful concept, each of them was linked separately. In the event of disagreement between assessors, consensus was reached by discussion. Meaningful concepts that could not be linked with the ICF were marked as “not covered” by the ICF. The analytic structure of the questionnaire was based on this linkage phase. Content density and diversity ratios were calculated to describe the content in relation to the ICF.^{22–26} Content density refers to the average number of concepts per item. The higher the value, the greater the number of meaningful concepts contained in one item on average. Content diversity ratio corresponds to the number of different ICF categories found in the questionnaire divided by the number of meaningful concepts they contain. A value close to zero indicates that several concepts of the instrument correspond to one and the same ICF category.

Content validity. The bandwidth index was calculated to assess to what extent the EAEQ covers the ICF environmental classification.^{22,23,25} Because of its specificity for the target population, we considered the 29 distinct categories of the ICF Core Set for adults with CP as denominator for the calculation.¹⁵ 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.

Measurement model. We considered each category identified in the analytic structure as a latent variable measuring an aspect of the environment. Based on the decision rules proposed in the literature to help identify the measurement model underlying a latent construct,²⁷ we concluded that the latent variables of the EAEQ should be considered as formative measurement models. Therefore, no further validity analysis based on inter-item correlations was required. This strategy was previously recommended.^{4,28}

Study design and population

This study is part of SPARCLE3 program,¹⁸ in which the EAEQ was developed. The eligible population consisted of young adults with CP, with a targeted age of 22-27 years at the time of data collection (2018-2020) and living in six European regions. They were sampled from population-based registries in south west and south east France, central Italy and western Sweden, or recruited from multiple sources in north west Germany and central Portugal.

Data collection

Trained research associates conducted standardized home interviews. The questionnaires were self-completed whenever possible, with assistance if required, or proxy-reported by a relative or a personal assistant who was closely involved in the daily life of the person with CP.²⁹

The following sociodemographic and impairment characteristics were collected: sex, age, region of residence, population size of place of residence, walking ability, hearing and visual impairment, speaking and communication skills. All response modalities are presented with the sample characteristics.

The EAEQ contains two types of items: items that collect the need for the EF (Needed/not needed) and its availability in case of need (Available/not available), and items that collect only availability, the need being considered *a priori* to be common to all individuals.

Statistical analysis

Sociodemographic, impairments and EAEQ data were summarized as counts and proportions. For each EAEQ item, we considered that responses of “Not needed” or “Needed and available” indicated that the environment was adequate for the need, while responses of “Needed and not available” reflected an unmet environmental need. The proportions of unmet needs were presented for each item by sex, walking ability, region, and population size of place of residence. Analyses were performed with STATA 14.2 (StataCorp, Texas, USA).

Results

EAEQ development and ICF-based content validity examination

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 S1 shows the administration structure of the EAEQ (life domain structure) with the response levels per item.

The EAEQ analytic structure is presented in Table 2. The two assessors individually identified 79 and 71 meaningful concepts, and linked 73 and 64 of these to the ICF environmental classification. Forty-four of these linking decisions were common. After consensus, 77 meaningful concepts were retained, of which six (7.8%) were considered “not covered”. The other 71 meaningful concepts 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”. 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 x 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. It includes communication restrictions with particular persons at home or in the community that are neither attitudes nor unsupportive relationships.

SPARCLE3 participants

The sample included 357 young adults with CP, mean age 24 years (SD 2 years), of whom 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.

Description of the environmental unmet needs

The responses to items across the EAEQ are described in Table 4. Eighteen items were answered by all participants. The response rate to the remaining 43 items was 96.0% to 99.7%. Overall, occurrence of unmet needs was low for the items that referred to home, to college/work/day placement, and to communication in the “Products and technology” chapter (<16% for each item). For each item of the “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 (with the exception of college/work/day placement items cited previously), more than 23% of participants reported an unmet need, which was as high as 35.3% for the “ramps in public places” item. Unmet environmental needs related to family and friends in the “Support and relationships”, “Attitudes”, and “Understand and be understood” chapters were rare, ranging from 0.6 to 10.2%. With regard

to people who were not so close, such as strangers in public places, healthcare professionals, colleagues and students, unmet needs were higher, as up to 35.7% of participants reported a lack of understanding from the general public/strangers of their speech/way of talking. For the “Services, systems and policies” chapter, unmet needs ranged from 9.3% for the item referring to safety of the local area to 53.1% for the item on information about accessibility of places in the area.

Unmet needs according to sociodemographic characteristics and impairment profile

For almost 70% of items (42/61), the proportion of declared 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 one with the largest sex differences, with more than a 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 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 (3,000 to 200,000 inhabitants) than in other locations.

Discussion

The EAEQ was developed from the ECEQ and supplemented with items identified as relevant to the target population of young adults with CP in several focus groups that included young adults with CP, families and health professionals. In an original way, the responses to the items measure the adequacy of the environment to individual needs expressed for 61 EFs. By linking the EAEQ items to the ICF and grouping all items corresponding to the same ICF hierarchical level, we created environmental categories, considered as formative measurement models. The responses showed a high variability of the proportion of young people with CP of varying severity who reported unmet environmental needs, ranging from 0.6% for the item “Help from family and friends to get around” to 53.1% for information about accessibility of public places. Among all the different services explored in the questionnaire, those related to communication and information matched needs very poorly. Overall, we observed a higher level of unmet needs among women, individuals unable to walk and those who lived in a middle-sized city.

The ICF is a recognized conceptual framework that provides a common language for clinical practice, research or health policy development.³³⁻³⁵ Indicators have therefore been developed

to judge the match between a given instrument and the ICF framework.²²⁻²⁶ Overall, 4 of the 5 chapters defined in the first level of the ICF environmental classification hierarchy are explored by specific items of the EAEQ with varying degrees of coverage, which was reflected by satisfactory content diversity and density ratios as well as by bandwidth index. These results are encouraging, as few instruments are available so far to measure the environment as a whole and as a concept in itself.^{22,24,26} “Natural environment and human-made changes to environment” was the only environmental chapter of the ICF not covered by the EAEQ, partly because the environmental factors it included are less proximal, and therefore cannot be measured using a self-reported questionnaire (e.g. air quality, pollution, etc...). This chapter was also absent from the environmental ICF Core Set for adults with CP.¹⁵ Some categories of the environmental ICF Core Set for adults with CP were not covered by the EAEQ, partly because they are remote from everyday concerns, such as attitudes of people in authority or societal attitudes. Finally, the EAEQ covered eight more ICF categories than the Core Set, thus allowing a fine-grained description of the environment.

The environmental measurement as proposed in the EAEQ has no equivalent. While the EAEQ measures the self-perceived proximal environment, other questionnaires measure the compliance of the environment (i.e. number of compliant facilities out of the total number of facilities measured) evaluated by external assessors, thus providing a more objective measure.^{36,37} In other settings, EFs were reported by adults with CP as barriers or facilitators in their daily lives.^{38,39} However, Noten et al³⁹ showed that products and technologies for personal indoor and outdoor mobility and transportation, as well as social support from close family and friends, were facilitators in participants’ daily lives. They were commonly rated as a met need among SPARCLE3 participants. The environmental barriers identified in Noten’s

study, namely “Design, construction and building products and technology of buildings for public use”, were the same EFs that were frequently rated as unmet in our study.

Study Limitations

During discussions in the focus groups, many EFs appeared to be relevant for young adults with CP. This led to a large set of items, which could make the questionnaire tedious to complete. The time required for completion was not recorded. However, the response rate on all items was over 96%, and missing values were randomly allocated. This reflects the acceptability of the EAEQ in this population and also the relevance of the questions asked. If we consider the environment at different levels, as suggested by the ecological theory,⁴⁰⁻⁴² the EFs identified in the EAEQ represent only those aspects of the environment that are close to the individual. The ecological model suggests that a more distant environment could also influence lifestyle and activities. No environmental factors referring to this distant environment were mentioned by the young adults with CP in the focus groups. However, we have chosen to focus the measurement on the individual proximal environment, and not to consider the macrosystem level. The ICF does not consider these hierarchical levels, but combines characteristics of the close and distant environment.

Conclusion

The EAEQ is an original measurement instrument, focusing on the perceived adequacy of the environment to the specific needs of young adults with CP and based on the ICF model. Its future use should make it possible to consider the physical, social and attitudinal environment as independent constructs for understanding the social behaviour of the target population and of other populations with various disabilities.

Author contributions

JA and LP developed the EAEQ questionnaire in Porto and Newcastle. CA co-led the SPARCLE3 study (principal investigator). CD supervised the field study. CP drafted the first manuscript. CA and NVEB co-supervised the study. VE advised on statistical analysis. All authors contributed to the interpretation of the results, reviewed and approved the final version of the manuscript.

References

1. World Health Organization (WHO). International Classification of Functioning, Disability and Health (ICF). Geneva: 2001.
2. World Health Organization. Measuring Health and Disability: Manual for WHO Disability Assessment Schedule WHODAS 2.0. World Health Organization; 2010.
3. Schneidert M, Hurst R, Miller J, Ustün B. The role of environment in the International Classification of Functioning, Disability and Health (ICF). *Disabil Rehabil.* 2003;25:588–95. doi: 10.1080/0963828031000137090
4. Whiteneck G, Dijkers MP. Difficult to Measure Constructs: Conceptual and Methodological Issues Concerning Participation and Environmental Factors. *Archives of Physical Medicine and Rehabilitation.* 2009;90:S22–35. doi: 10.1016/j.apmr.2009.06.009
5. Keysor J, Jette A, Haley S. Development of the home and community environment (HACE) instrument. *J Rehabil Med.* 2005;37:37–44. doi: 10.1080/16501970410014830

6. Gething L, Wheeler B, Cote J, Furnham A, Hudek-Knezevic J, Kumpf M, et al. An international validation of the interaction with disabled persons scale. *Int J Rehabil Res.* 1997;20:149–58. doi: 10.1097/00004356-199706000-00004
7. Shumway-Cook A, Patla A, Stewart AL, Ferrucci L, Ciol MA, Guralnik JM. Assessing environmentally determined mobility disability: self-report versus observed community mobility. *J Am Geriatr Soc.* 2005;53:700–4. doi:10.1111/j.1532-5415.2005.53222.x
8. Stark S, Hollingsworth HH, Morgan KA, Gray DB. Development of a measure of receptivity of the physical environment. *Disabil Rehabil.* 2007;29:123–37. doi: 10.1080/09638280600731631
9. Reinhardt J, Miller J, Stucki ProfDr med. G, Sykes C, Gray D. Measuring impact of environmental factors on human functioning and disability: A review of various scientific approaches. *Disability and rehabilitation.* 2011;33:2151–65. doi: 10.3109/09638288.2011.573053
10. Whiteneck GG, Harrison-Felix CL, Mellick DC, Brooks CA, Charlifue SB, Gerhart KA. Quantifying environmental factors: a measure of physical, attitudinal, service, productivity, and policy barriers. *Arch Phys Med Rehabil.* 2004;85:1324–35. doi: 10.1016/j.apmr.2003.09.027
11. Gray DB, Hollingsworth HH, Stark S, Morgan KA. A subjective measure of environmental facilitators and barriers to participation for people with mobility limitations. *Disabil Rehabil.* 2008;30:434–57. doi: 10.1080/09638280701625377
12. Fougeyrollas P, Noreau L, St G, Boschen M. Measure of the Quality of Environment Version 2. 1999;9.

13. Donovan, Doyle A. Measuring Activity and Participation of People with Disabilities – An Overview. 2006;
14. McIntyre S, Goldsmith S, Webb A, Ehlinger V, Hollung SJ, McConnell K, et al. Global prevalence of cerebral palsy: A systematic analysis. *Developmental Medicine & Child Neurology*. 2022;64:1494–506. doi: 10.1111/dmcn.15346
15. Noten S, Selb M, Troenosemito LAA, Thorpe DE, Rodby-Bousquet E, van der Slot WMA, et al. ICF Core Sets for the assessment of functioning of adults with cerebral palsy. *Dev Med Child Neurol*. 2022;64:569–77. doi: 10.1111/dmcn.15104
16. Colver A, SPARCLE Group. Study protocol: SPARCLE--a multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. *BMC Public Health*. 2006;6:105. doi: 10.1186/1471-2458-6-105
17. Colver AF, Dickinson HO, SPARCLE group. Study protocol: determinants of participation and quality of life of adolescents with cerebral palsy: a longitudinal study (SPARCLE2). *BMC Public Health*. 2010;10:280. doi: 10.1186/1471-2458-10-280
18. Arnaud C, Duffaut C, Fauconnier J, Schmidt S, Himmelmann K, Marcelli M, et al. Determinants of participation and quality of life of young adults with cerebral palsy: longitudinal approach and comparison with the general population - SPARCLE 3 study protocol. *BMC Neurol*. 2021;21:254. doi: 10.1186/s12883-021-02263-z
19. Dickinson HO, Colver A, Sparcle Group. Quantifying the physical, social and attitudinal environment of children with cerebral palsy. *Disabil Rehabil*. 2011;33:36–50. doi: 10.3109/09638288.2010.485668

20. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, et al. Linking health-status measurements to the international classification of functioning, disability and health. *J Rehabil Med.* 2002;34:205–10. doi: 10.1080/165019702760279189
21. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustün B, Stucki G. ICF linking rules: an update based on lessons learned. *J Rehabil Med.* 2005;37:212–8. doi: 10.1080/16501970510040263
22. Alviar MJ, Olver J, Brand C, Hale T, Khan F. Do patient-reported outcome measures used in assessing outcomes in rehabilitation after hip and knee arthroplasty capture issues relevant to patients? Results of a systematic review and ICF linking process. *J Rehabil Med.* 2011;43:374–81. doi: 10.2340/16501977-0801
23. Geyh S, Cieza A, Kollerits B, Grimby G, Stucki G. Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review. *Qual Life Res.* 2007;16:833–51. doi: 10.1007/s11136-007-9174-8
24. Yang M, Luo L, Hao Q, Dong B. Content comparison of self-reported disability measures for the elderly according to the international classification of functioning, disability and health. *Disabil Rehabil.* 2014;36:884–93. doi: 10.3109/09638288.2013.822571
25. Chung P, Yun SJ, Khan F. A comparison of participation outcome measures and the International Classification of Functioning, Disability and Health Core Sets for traumatic brain injury. *J Rehabil Med.* 2014;46:108–16. doi: 10.2340/16501977-1257
26. Stamm T, Geyh S, Cieza A, Machold K, Kollerits B, Kloppenburg M, et al. Measuring functioning in patients with hand osteoarthritis--content comparison of questionnaires

- based on the International Classification of Functioning, Disability and Health (ICF).
Rheumatology (Oxford). 2006;45:1534–41. doi: 10.1093/rheumatology/ke1133
27. Kean J, Malec JF. Towards a Better Measure of Brain Injury Outcome: New Measures or a New Metric? *Archives of Physical Medicine and Rehabilitation*. 2014;95:1225–8. doi: 10.1016/j.apmr.2014.03.023
 28. Dickinson HO, Colver AF. Measurement of the Environment of People With Disabilities. *Archives of Physical Medicine and Rehabilitation*. 2010;91:1310–1. doi: 10.1016/j.apmr.2010.03.012
 29. Scott HM, Havercamp SM. Comparisons of self and proxy report on health-related factors in people with intellectual disability. *J Appl Res Intellect Disabil*. 2018;31:927–36. doi: 10.1111/jar.12452
 30. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol*. 1997;39:214–23. doi: 10.1111/j.1469-8749.1997.tb07414.x
 31. Pennington L, Virella D, Mjøen T, da Graça Andrada M, Murray J, Colver A, et al. Development of The Viking Speech Scale to classify the speech of children with cerebral palsy. *Res Dev Disabil*. 2013;34:3202–10. doi: 10.1016/j.ridd.2013.06.035
 32. Barty E, Caynes K, Johnston LM. Development and reliability of the Functional Communication Classification System for children with cerebral palsy. *Dev Med Child Neurol*. 2016;58:1036–41. doi: 10.1111/dmcn.13124
 33. Ustün TB, Chatterji S, Bickenbach J, Kostanjsek N, Schneider M. The International Classification of Functioning, Disability and Health: a new tool for understanding

- disability and health. *Disabil Rehabil.* 2003;25:565–71. doi:
10.1080/0963828031000137063
34. Kostanjsek N. Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. *BMC Public Health.* 2011;11:S3. doi: 10.1186/1471-2458-11-S4-S3
35. Leonardi M, Lee H, Kostanjsek N, Fornari A, Raggi A, Martinuzzi A, et al. 20 Years of ICF—International Classification of Functioning, Disability and Health: Uses and Applications around the World. *International Journal of Environmental Research and Public Health.* 2022;19:11321. doi: 10.3390/ijerph191811321
36. Evcil AN. Wheelchair accessibility to public buildings in Istanbul. *Disabil Rehabil Assist Technol.* 2009;4:76–85. doi: 10.1080/17483100802543247
37. Welage N, Liu KPY. Wheelchair accessibility of public buildings: a review of the literature. *Disabil Rehabil Assist Technol.* 2011;6:1–9. doi:
10.3109/17483107.2010.522680
38. Boucher N, Dumas F, B. Maltais D, Richards CL. The influence of selected personal and environmental factors on leisure activities in adults with cerebral palsy. *Disability and Rehabilitation.* 2010;32:1328–38. doi: 10.3109/09638280903514713
39. Noten S, Rodby-Bousquet E, Limsakul C, Tipchatyotin S, Visser F, Grootoonk A, et al. An international clinical perspective on functioning and disability in adults with cerebral palsy. *Disability and Health Journal.* 2022;15:101318. doi: 10.1016/j.dhjo.2022.101318

40. Bronfenbrenner U. *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press; 1981.
41. Olivier-Pijpers VC, Cramm JM, Buntinx WHE, Nieboer AP. Organisational environment and challenging behaviour in services for people with intellectual disabilities: A review of the literature. *Alter*. 2018;12:238–53. doi: 10.1016/j.alter.2018.06.004
42. Olivier-Pijpers VC, Cramm JM, Nieboer AP. Influence of the organizational environment on challenging behaviour in people with intellectual disabilities: Professionals' views. *Journal of Applied Research in Intellectual Disabilities*. 2019;32:610–21. doi: 10.1111/jar.12555

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

<p><i>Family, service providers, and public:</i></p> <ul style="list-style-type: none"> - Understanding of needs and positive attitudes - Communicating using language that is easy to understand
<p><i>Availability of:</i></p> <ul style="list-style-type: none"> - Appropriate education and employment - Assistive technology in education
<p>Accessibility of the built environment including streets, buildings, and transport</p>
<p>Adaptation and availability of leisure facilities</p>
<p>Flexibility of personal assistance personnel and consistency and reliability of providers of support</p>
<p>Access to adequate health services</p>
<p>Financial support programs</p>
<p><i>Access to:</i></p> <ul style="list-style-type: none"> - Internet connection - Social media

CP: Cerebral palsy; EAEQ: European Adult Environment Questionnaire

Table 2. EAEQ analytic structure based on the linkage procedure with the ICF environmental classification

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	<i>E155</i>	
2. Adaptations to the entrance of your home	<i>E155</i>	
3. Adapted bathroom	<i>E155</i>	
4. Adaptations to other rooms (e.g. work surfaces in kitchen)	<i>E155</i>	
Products and technology for personal use in daily living	E115	1
5. Aids/adapted equipment for personal care, cooking, housekeeping etc.	<i>E115</i>	
Products and technology for communication	E125	2
6. Communication aids at home	<i>E125</i>	
10. Communication aids at work/college/day placement	<i>E125</i>	
Products and technology for education and for employment	E130 / E135	1
9. Adapted equipment (e.g. computer)	<i>E130 / E135</i>	
Products and technology for personal indoor and outdoor mobility and transportation	E120	2
18. Adapted vehicle for getting around	<i>E120</i>	
22. Modified wheelchair	<i>E120</i>	
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	<i>E150</i>	
8. Adapted toilets at work/college/day placement	<i>E150</i>	
12. Ramps in public places	<i>E150</i>	
13. Adapted toilets or toilet facilities	<i>E150</i>	
14. Lifts/escalators	<i>E150</i>	
15. Adapted doorways	<i>E150</i>	
17. 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?	<i>E150 / E140</i>	
Products and technology of land development	E160	2
16. Accessible pavements in your town or village center	<i>E160</i>	
57. Are public places accessible for you to move around?	<i>E160</i>	
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	<i>E325</i>	

39. Do people around you (personal assistant/students/colleagues/healthcare professionals) help you to do things at work/college/day placement?	<i>E325 / E340 / E355</i>	
Immediate family, extended family, friends	E310 / E315 / E320	3
23. Help from family and friends to get around	<i>E310 / E315 / E320</i>	
38. Do family and friends help you to do things at home?	<i>E310 / E315 / E320</i>	
44. Do you get emotional support from family and friends?	<i>E310 / E315 / E320</i>	
Personal care providers and personal assistants	E340	2
31. A personal assistant to help you at home	<i>E340</i>	
32. A personal assistant to help you at work/college/day placement	<i>E340</i>	
Strangers	E345	1
40. Do people in public places help you to do things?	<i>E345</i>	
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	<i>E425 / E450</i>	
42. Do students/colleagues/healthcare professionals have a positive attitude towards you?	<i>E425 / E450</i>	
53. Do staff at college/placement/work understand your needs (medical condition)?	<i>E425</i>	
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 towards you?	<i>E410 / E415 / E420</i>	
45. Do your family and friends encourage you to do things and to try things out?	<i>E410 / E415 / E420</i>	
Individual attitudes of strangers	E445	1
43. Do the general public/strangers have a positive attitude towards you?	<i>E445</i>	
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.	<i>E570</i>	
34. Financial support/grants from the government/council for: Home modifications	<i>E570</i>	
35. Financial support/grants from the government/council for: A personal assistant	<i>E570</i>	
36. Financial support/grants from the government/council for: Travel/transport	<i>E570</i>	
37. Financial support/grants from the government/council for: Leisure activities/holidays	<i>E570</i>	
Associations and organizational services, systems and policies	E555	1
29. Support groups in your area	<i>E555</i>	
General social support services, systems and policies	E575	1
30. Counseling services	<i>E575</i>	
Health services, systems and policies	E580	4
24. Specialized therapy services, such as: Physiotherapy	<i>E580</i>	
25. Specialized therapy services, such as: Speech therapy	<i>E580</i>	
26. Specialized therapy services, such as: Occupational therapy	<i>E580</i>	

27. Specialized therapy services, such as: A specialist doctor who knows about your condition	<i>E580</i>	
Communication services, systems and policies	E535	5
46. Do you have access to social media? (e.g. texting, FB, Twitter)	<i>E535</i>	
58. Is information about services easy to understand?	<i>E535</i>	
59. Is information about activities in your area, e.g. cinema, easy to understand?	<i>E535</i>	
60. Is there information about accessibility of places in your area?	<i>E535</i>	
61. Is information about employment/education available to you?	<i>E535</i>	
Open space planning services, systems and policies	E520	1
19. Accessible car parking in places where you need to park	<i>E520</i>	
Transportation services, systems and policies	E540	2
20. Adequate public transport (buses/trains/taxis)	<i>E540</i>	
21. Accessible public transport (buses/trains/taxis)	<i>E540</i>	
Civil protection services, systems and policies	E545	2
55. Is public transport safe?	<i>E545</i>	
56. Is your local area safe?	<i>E545</i>	
Education and training services, systems and policies	E585	1
54. Does your college/employer/day placement provide for your needs?	<i>E585</i>	
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/healthcare 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/healthcare professionals) communicate in a way that is easy to understand?		
52. Do the public/strangers communicate in a way that is easy to understand?		

EAEQ: European Adult Environment Questionnaire; ICF: International Classification of Functioning, Disability and Health; FB: Facebook; nc: not covered

by ICF

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
Population size of place of residence		
<3,000 inhabitants	70	19.7
3,000–200,000 inhabitants	159	44.8
>200,000 inhabitants	126	35.5
<i>Missing</i>	2	
Age (years)		
	<i>Mean</i>	<i>SD</i>
	24	2
	<i>Min</i>	<i>Max</i>
	19	28
Walking ability (GMFCS³⁰)		
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
<i>Missing</i>	1	
Visual impairment		
No	243	68.0
Yes	114	32.0
Speaking ability (VSS³¹)		
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 (FCCS³²)		
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

SPARCLE3: Study of PARTICipation of children with Cerebral palsy Living in Europe – 3rd wave; CP: Cerebral palsy; GMFCS: Gross Motor Function Classification System;³⁰ VSS: Viking Speech Scale;³¹ FCCS: Functional Communication Classification System³²

Table 4. Responses to EAEQ items of young adults with CP participating in the SPARCLE3 study (N=357)

Headings of ICF chapters and ICF categories	Includes items on need	No. (%) of respondents	Met need (%)			Unmet need (%)
			Not needed	Needed and available	Total	Needed and not available
Products and technology						
Design, construction and building products and technology of buildings for private use						
1. Enlarged rooms or extensions	Y	357 (100)	57.4	30.8	88.2	11.8
2. Adaptations to the entrance of your home	Y	357 (100)	57.1	34.2	91.3	8.7
3. Adapted bathroom	Y	357 (100)	42.3	42.0	84.3	15.7
4. Adaptations to other rooms (e.g. work surfaces in kitchen)	Y	357 (100)	74.0	14.9	88.8	11.2
Products and technology for personal use in daily living						
5. Aids/adapted equipment for personal care, cooking, housekeeping etc.	Y	356 (99.7)	58.4	29.5	87.9	12.1
Products and technology for communication						
6. Communication aids at home	Y	357 (100)	83.2	12.0	95.2	4.8
10. Communication aids at work/college/day placement	Y	352 (98.6)	81.3	12.5	93.8	6.3
Products and technology for education and for employment						
9. Adapted equipment (e.g. computer)	Y	352 (98.6)	71.9	22.4	94.3	5.7
Products and technology for personal indoor and outdoor mobility and transportation						
18. Adapted vehicle for getting around	Y	357 (100)	45.4	35.0	80.4	19.6
22. Modified wheelchair	Y	357 (100)	49.0	46.8	95.8	4.2
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	Y	352 (98.6)	56.3	34.4	90.6	9.4
8. Adapted toilets at work/college/day placement	Y	352 (98.6)	59.1	34.9	94.0	6.0
12. Ramps in public places	Y	354 (99.2)	46.3	18.4	64.7	35.3
13. Adapted toilets or toilet facilities	Y	357 (100)	58.3	16.8	75.1	24.9
14. Lifts/escalators	Y	357 (100)	40.9	35.9	76.8	23.3
15. Adapted doorways	Y	357 (100)	54.1	22.1	76.2	23.8
17. 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?	Y	354 (99.2)	46.1	30.2	76.3	23.7
Products and technology of land development						
16. Accessible pavements in your town or village center	Y	356 (99.7)	43.5	22.8	66.3	33.7
57. Are public places accessible for you to move around?	N	355 (99.4)	-	70.7	70.7	29.3
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	Y	352 (98.6)	48.0	43.2	91.2	8.8
39. Do people around you (personal assistant/students/colleagues/healthcare professionals) help you to do things at work/college/placement?	Y	355 (99.4)	28.5	67.9	96.3	3.7
Immediate family, extended family, friends						
23. Help from family and friends to get around	Y	356 (99.7)	30.3	69.1	99.4	0.6
38. Do family and friends help you to do things at home?	Y	356 (99.7)	19.7	78.1	97.8	2.3
44. Do you get emotional support from family and friends?	N	356 (99.7)	-	96.6	96.6	3.4
Personal care providers and personal assistants						
31. A personal assistant to help you at home	Y	357 (100)	58.8	25.8	84.6	15.4
32. A personal assistant to help you at work/college/day placement	Y	353 (98.9)	60.1	33.1	93.2	6.8
Strangers						
40. Do people in public places help you to do things?	Y	357 (100)	49.9	38.4	88.2	11.8
Attitudes						
Individual attitudes of acquaintances, peers, colleagues, neighbors and community members / of health professionals						
28. Teachers, therapists and doctors who listen to your views	Y	353 (98.9)	23.2	64.0	87.3	12.8
42. Do students/colleagues/healthcare professionals have a positive attitude towards you?	N	355 (99.4)	-	95.2	95.2	4.8
53. Do staff at college/placement/work understand your needs (medical condition)?	N	343 (96)	-	87.8	87.8	12.2
Individual attitudes of immediate family members / of extended family members / of friends						
41. Do family and friends have a positive attitude towards you?	N	357 (100)	-	97.2	97.2	2.8
45. Do your family and friends encourage you to do things and to try things out?	N	355 (99.4)	-	92.7	92.7	7.3
Individual attitudes of strangers						
43. Do the general public/strangers have a positive attitude towards you?	N	350 (98)	-	72.9	72.9	27.1
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.	Y	357 (100)	40.1	48.7	88.8	11.2
34. Financial support/grants from the government/council for: Home modifications	Y	357 (100)	56.0	24.1	80.1	19.9
35. Financial support/grants from the government/council for: A personal assistant	Y	357 (100)	59.9	24.9	84.9	15.1
36. Financial support/grants from the government/council for: Travel/transport	Y	357 (100)	47.6	28.0	75.6	24.4
37. Financial support/grants from the government/council for: Leisure activities/holidays	Y	356 (99.7)	55.9	15.2	71.1	28.9
Associations and organizational services, systems and policies						
29. Support groups in your area	Y	354 (99.2)	69.2	12.4	81.6	18.4
General social support services, systems and policies						
30. Counseling services	Y	355 (99.4)	55.8	26.8	82.5	17.5

Health services, systems and policies						
24. Specialized therapy services, such as: Physiotherapy	Y	356 (99.7)	18.0	65.7	83.7	16.3
25. Specialized therapy services, such as: Speech therapy	Y	356 (99.7)	71.1	13.2	84.3	15.7
26. Specialized therapy services, such as: Occupational therapy	Y	354 (99.2)	54.2	28.5	82.8	17.2
27. Specialized therapy services, such as: A specialist doctor who knows about your condition	Y	357 (100)	18.8	68.4	87.1	12.9
Communication services, systems and policies						
46. Do you have access to social media? (e.g. texting, FB, Twitter)	N	355 (99.4)	-	70.7	70.7	29.3
58. Is information about services easy to understand?	N	354 (99.2)	-	59.6	59.6	40.4
59. Is information about activities in your area, e.g. cinema, easy to understand?	N	353 (98.9)	-	71.4	71.4	28.6
60. Is there information about accessibility of places in your area?	N	343 (96)	-	46.9	46.9	53.1
61. Is information about employment/education available to you?	N	343 (96)	-	53.6	53.6	46.4
Open space planning services, systems and policies						
19. Accessible car parking in places where you need to park	Y	356 (99.7)	36.2	37.4	73.6	26.4
Transportation services, systems and policies						
20. Adequate public transport (buses/trains/taxis)	Y	355 (99.4)	44.2	36.6	80.9	19.2
21. Accessible public transport (buses/trains/taxis)	Y	354 (99.2)	46.3	33.3	79.7	20.3
Civil protection services, systems and policies						
55. Is public transport safe?	N	351 (98)	-	67.8	67.8	32.2
56. Is your local area safe?	N	355 (99.4)	-	90.7	90.7	9.3
Education and training services, systems and policies						
54. Does your college/employer/day placement provide for your needs?	N	341 (96)	-	81.2	81.2	18.8
Understand and be understood						
47. Do your family and friends understand your speech/way of talking?	N	352 (98.6)	-	89.8	89.8	10.2
48. Do people around you (personal assistant/students/colleagues/healthcare professionals) understand your speech/way of talking?	N	353 (98.9)	-	83.3	83.3	16.7
49. Do the public/strangers understand your speech/way of talking?	N	353 (98.9)	-	64.3	64.3	35.7
50. Do your family and friends communicate in a way that is easy to understand?	N	356 (99.7)	-	96.1	96.1	3.9
51. Do people around you (personal assistant/students/colleagues/healthcare professionals) communicate in a way that is easy to understand?	N	354 (99.2)	-	91.8	91.8	8.2
52. Do the public/strangers communicate in a way that is easy to understand?	N	353 (98.9)	-	73.4	73.4	26.6

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; Y: Yes; N: No

Table 5. 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)

Headings of ICF chapters and ICF categories	Unmet need (%)		Unmet need (%)		Unmet need (%)					Unmet need (%)		
	Sex		GMFCS level		Region					Population size of place of residence		
	Male	Female	I, II, III	IV, V	Fr	De	It	Pt	Se	<3,000 inhabitants	3,000 – 200,000 inhabitants	>200,000 inhabitants
	n=200	n=157	n=220	n=137	n=88	n=110	n=24	n=105	n=30	n=70	n=159	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 (e.g. 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 (e.g. 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
17. 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?	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/healthcare 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
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/healthcare professionals have a positive attitude towards 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 towards 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 towards 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
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? (e.g. 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, e.g. 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
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/healthcare 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/healthcare 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

SPARCLE3: Study of PARTICipation of children with Cerebral palsy Living in Europe – 3rd wave; CP: Cerebral palsy; EAEQ: European Adult

Environment Questionnaire; GMFCS: Gross Motor Function Classification System; ICF: International Classification of Functioning, Disability

and Health; FB: Facebook; Fr: France; De: Germany; It: Italy; Pt: Portugal; Se: Sweden

* Two young adults did not fulfil their place of residence

Table S1. Life domains structure of the EAEQ with the 61 selected items

Domains and sub-domains of the life structure version of the EAEQ	Includes items on need
Home	
1. Enlarged rooms or extensions	Y
2. Adaptations to the entrance of your home	Y
3. Adapted bathroom	Y
4. Adaptations to other rooms (e.g. work surfaces in kitchen)	Y
5. Aids/adapted equipment for personal care, cooking, housekeeping etc.	Y
6. Communication aids at home	Y
Work/college/university/day placement	
7. Adaptations to make all areas at college/work accessible	Y
8. Adapted toilets	Y
9. Adapted equipment (e.g. computer)	Y
10. Communication aids at work/college/day placement	Y
11. Extra time to do what you need to do	Y
Public places	
12. Ramps in public places	Y
13. Adapted toilets or toilet facilities	Y
14. Lifts/escalators	Y
15. Adapted doorways	Y
16. Accessible pavements in your town or village center	Y
17. 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?	Y
Transport	
18. Adapted vehicle for getting around	Y
19. Accessible car parking in places where you need to park	Y
20. Adequate public transport (buses/trains/taxis)	Y
21. Accessible public transport (buses/trains/taxis)	Y
22. Modified wheelchair	Y

23. Help from family and friends to get around	Y
Services	
Healthcare	
24. Specialized therapy services, such as: Physiotherapy	Y
25. Specialized therapy services, such as: Speech therapy	Y
26. Specialized therapy services, such as: Occupational therapy	Y
27. Specialized therapy services, such as: A specialist doctor who knows about your condition	Y
28. Teachers, therapists and doctors who listen to your views	Y
29. Support groups in your area	Y
30. Counseling services	Y
Personal assistants	
31. A personal assistant to help you at home	Y
32. A personal assistant to help you at work/college/day placement	Y
Finance	
33. Financial support/grants from the government/council for: Equipment such as wheelchairs, communication aids, hoists, bathing aids etc.	Y
34. Financial support/grants from the government/council for: Home modifications	Y
35. Financial support/grants from the government/council for: A personal assistant	Y
36. Financial support/grants from the government/council for: Travel/transport	Y
37. Financial support/grants from the government/council for: Leisure activities/holidays	Y
People	
38. Do family and friends help you to do things at home?	Y
39. Do people around you (personal assistant/students/colleagues/healthcare professionals) help you to do things at work/college/placement?	Y
40. Do people in public places help you to do things?	Y
41. Do family and friends have a positive attitude towards you?	N
42. Do students/colleagues/healthcare professionals have a positive attitude towards you?	N
43. Do the general public/strangers have a positive attitude towards you?	N
44. Do you get emotional support from family and friends?	N
45. Do your family and friends encourage you to do things and to try things out?	N
46. Do you have access to social media? (e.g. texting, FB, Twitter)	N
47. Do your family and friends understand your speech/way of talking?	N
48. Do people around you (personal assistant/students/colleagues/healthcare professionals) understand your speech/way of talking?	N

49. Do the public/strangers understand your speech/way of talking?	N
50. Do your family and friends communicate in a way that is easy to understand?	N
51. Do people around you (personal assistant/students/colleagues/healthcare professionals) communicate in a way that is easy to understand?	N
52. Do the public/strangers communicate in a way that is easy to understand?	N
53. Do staff at college/placement/work understand your needs (medical condition)?	N
54. Does your college/employer/day placement provide for your needs?	N
55. Is public transport safe?	N
56. Is your local area safe?	N
57. Are public places accessible for you to move around?	N
Information	
58. Is information about services easy to understand?	N
59. Is information about activities in your area, e.g. cinema, easy to understand?	N
60. Is there information about accessibility of places in your area?	N
61. Is information about employment/education available to you?	N

EAEQ: European Adult Environment Questionnaire; FB: Facebook ; Y: Yes; N: No