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Employment and higher education in young adults with cerebral palsy: a cross-sectional analysis of the SPARCLE study

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ABSTRACT

Introduction For young people with disabilities, access to higher education and employment should lead to improved personal self-esteem and well-being and, in the long run, to increased inclusion in society. Our aims were to describe the education and employment status of young adults with cerebral palsy (CP), to investigate the personal and contextual factors, including prior mainstream education, that most influence these statuses, and to study to what extent employment affects the quality of life (QoL).

Methods We used data from the SPARCLE3 cross-sectional study, collected in 2018–2020 in five European regions. Eligible participants were adults with CP, 22–27 years, without moderate to profound intellectual disability. Outcomes were education and employment statuses. Unconditional logistic regressions were performed to test the association with impairments, comorbidities, personal and family characteristics and environmental factors. QoL scores (WHOQOL-bref score 0–100) were compared using linear regressions.

Results Of the 227 participants, 21.6% had a tertiary degree, 35.2% were employed. The likelihood of being employed or of having a tertiary degree was reduced by more than 75% for those with more severe gross motor limitations or communication/speech difficulties. Those with a tertiary degree were more likely to be employed (OR 9.37 (95% CI 2.87 to 30.64)) while accessible car parking was the only associated environmental factor (OR 2.92 (95% CI 1.19 to 7.18)). Prior mainstream schooling increased the odds of being employed 16-fold. Individuals who were employed reported an 8-point increase in the physical and psychological well-being domains of QoL compared with those who were unemployed.

Conclusions The employment situation of young adults with CP can still be improved, but our findings encourage the implementation of inclusive policies from an early age.

INTRODUCTION

Throughout their lives, individuals with disabilities face numerous barriers, limiting their involvement in life situations and social roles.[1] In recent decades, responses to these restrictions have evolved alongside the conceptualisation of disability. Historically, this concept was based on a medical and individual model, considering disability and its associated limitations as the result of impairments (physical, sensory, psychic and mental), and providing for segregated solutions such as residential institutions and special schools.[2] Since the 1990s, disabled peoples' movements[3 4] and researchers[5] have shifted the conceptual definition of disability from a 'medical model'to a'social model'. In the latter, disability is not the result of the individual's incapacity but rather of inadequacy of the environment for their disability, thus challenging society to accommodate impairment. As disability should be viewed as neither purely medical nor purely social, the International Classification of Functioning, Disability and Health (ICF) proposed in 2001a balanced multidimensional concept that sees disability as a dynamic interaction between 'body functions and structures'and 'personal and environmental contextual factors' that results in reduced activities of daily living and limited participation in social activities.[6 7] Disability is thus related to the inadequacy of the physical, social and attitudinal environment to the complex needs of people with reduced functioning. Similarly to their counterparts in the general population to whom the ICF model also refers, people with disabilities may report varying levels of activity and participation, but these are increasingly reduced with increasing severity of impairment.[8–12] Identifying and addressing societal barriers in the environment, and focusing on community and educational inclusion together with more interactive medical approaches, can help improve participation.[13]

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ We found three articles on employment or higher education in adults with cerebral palsy. Studies have shown lower employment rates in individuals with severe intellectual and physical disability, epilepsy, fatigue and low educational level, while factors influencing access to higher education remain to be investigated. No previous studies have examined the role of environmental factors and mainstream schooling on access to employment or higher education, or the extent to which being employed can increase quality of life.

WHAT THIS STUDY ADDS

⇒ This cross-sectional study sheds new light on the barriers and levers for accessing employment or higher education in young adults with cerebral palsy. We showed that severe impairments of gross motor function and communication are the two main factors that limit employment or completion of higher education. While we add to existing evidence for the role of higher education in access to employment, we are the first to investigate and observe that having attended a mainstream school during childhood or continued mainstream education until adolescence is a powerful lever for access to employment. To our knowledge, this study is the first to examine the associations between environment and employment and higher education, and to report the positive role of accessibility to car parking when needed on employment or higher education status. Lastly, we are the first to report the positive impact of employment on the physical and psychological quality of life of young adults with cerebral palsy.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Studies focusing on young adults with cerebral palsy demonstrate that their employment situation can still be improved. Our findings suggest that including young people with disabilities in society from an early age and keeping them there as much as possible promotes their access to higher education and employment in young adulthood. Given the positive impact of employment on their quality of life, this encourages the implementation of inclusive policies from an early age.

The literature reports that effective inclusion in society of young people with disabilities generates opportunities for personal development and improves well-being, notably for individuals with cerebral palsy (CP).[14] CP is the most frequent childhood-onset physical disability. It results in permanent disorders of movement, posture and motor function that may be associated with sensory, perceptual, cognitive, communication and behavioural disorders, epilepsy and secondary musculoskeletal problems.[15] Previous research mainly focused on children reporting significant differences between countries in public policies towards disability and their implementation, support and care services, education[16] or accessibility, which provided a better understanding of the impact of an unsupportive environment on engagement in social roles. However, knowledge on participation in adulthood remains scarce, although it is now estimated that a large majority of children with CP will experience this period in their lives.[17 18] Two normative social roles for young adults are enrolment in higher education and/or getting a worthwhile job, both areas where those with disabilities may experience restrictions or barriers. Reported rates of employment in adults with CP range from 17% to 53%, markedly lower than that of the general population in Western countries.[19–25] Factors influencing the employment rate of young adults with CP include severe intellectual and physical disability, epilepsy, fatigue and low educational level,[22 24 26] while factors influencing access to higher education remain to be investigated. Although research has yielded limited evidence, we may assume that experiences in inclusive settings from an early age, particularly mainstream schooling, bring personal satisfaction with life, enhance social roles and increase post-secondary education choice and employment aspirations.

We aimed to describe the higher education and employment status of young adults with CP, to investigate the role of personal, sociodemographic and environmental factors, to determine whether mainstream education in childhood and/or adolescence had a significant impact and to study to what extent being employed was associated with increased quality of life (QoL).

MATERIALS AND METHODS

Study design, data source and study population

We used data from the SPARCLE3 study, a multicentre European observational population-based study designed to investigate the impact of the environment on participation and QoL of young adults with CP, and to determine predictors of successful young adulthood in educational, professional, health and social fields. The study design has been described elsewhere.[27] Briefly, the eligible population consisted of young adults, aged 22–27 years at the time of data collection in 2018–2020, with a diagnosis of CP according to the definition of the Surveillance of Cerebral Palsy in Europe network.[28] They lived in France, Germany, Sweden and Italy for those who previously participated in the SPARCLE cohort as children (aged 8–12 years in 2004–2005, SPARCLE1)[29] and/or adolescents (aged 13–17 years in 2009–2010, SPARCLE2),[30] and in Portugal for those who had not previously participated. Additional individuals were invited to participate in all regions, resulting in a total sample of 310 participants, 164 of whom had participated in previous waves of the SPARCLE cohort. For this analysis, the sample was restricted to those without moderate to profound intellectual impairment (IQ ≥50) at inclusion and who had the capacity to work (figure 1).

Patient and public involvement

Patients were not involved in the design and the conduct of this study. However, young adults with CP were involved through focus group discussions and interviews in identifying outcomes relevant to the development of new environmental and participation measurement instruments (European Adult Environment Questionnaire (EAEQ) and QYPP-YA, respectively) used in the SPARCLE3 study.

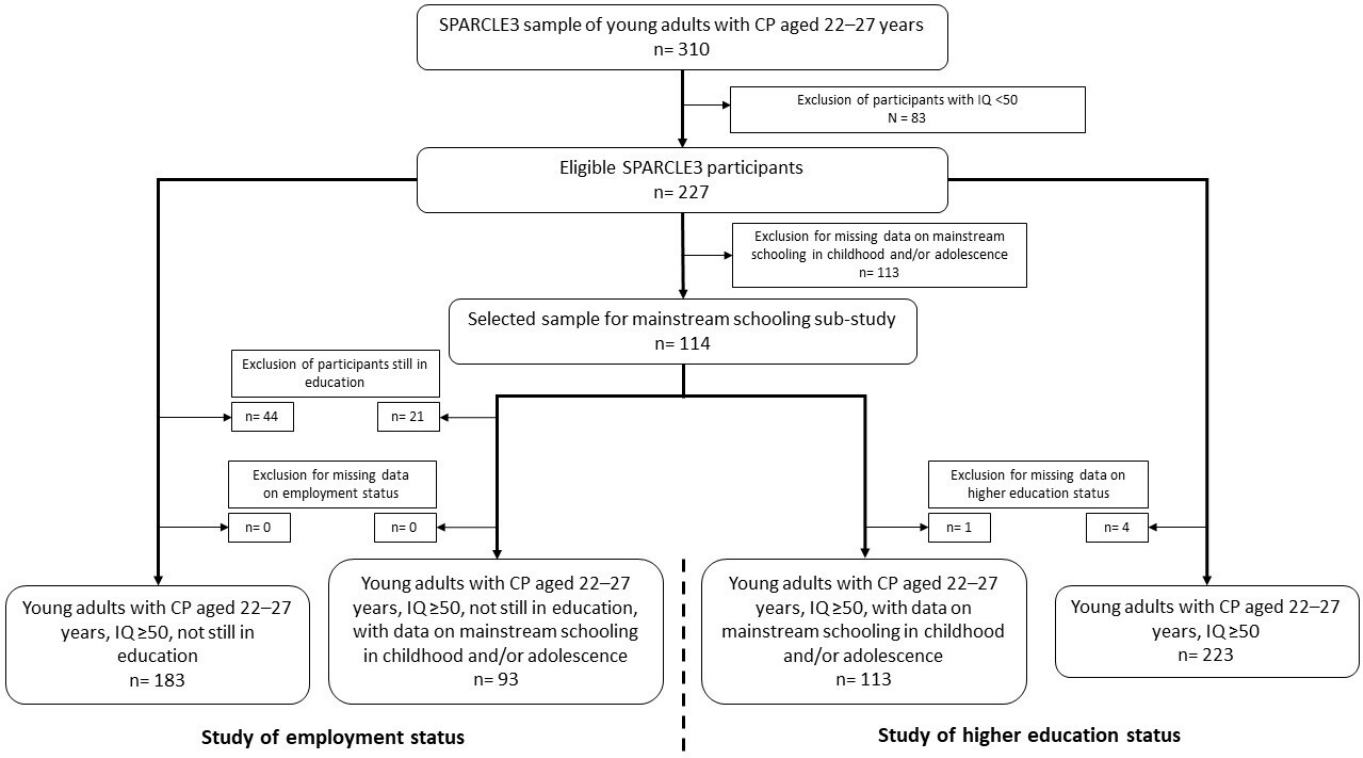

Figure 1 Description of the selection of samples used for the analyses—SPARCLE3—France, Germany, Italy, Portugal and Sweden, 2018–2020. CP, cerebral palsy.

Ethics statement

We sought the relevant ethical and regulatory authorisations in each country. All young people with CP or their legal representatives gave written informed consent to participate, or non-opposition where appropriate.

Procedures and data collected

Trained research associates visited young adults with CP and conducted interviews under identical conditions in each region. Whenever possible, the questionnaires were self-completed, with the researcher's assistance when needed. When self-reports were not possible, even with help, proxy reports were obtained from an individual (parent, personal assistant or partner) significantly involved in the daily life of the person with CP.

At the interview, young adults with CP were asked if they were employed, still in education or unemployed. Those who had a job stated whether they were paid, whether they were working full-time or part-time, if tasks were appropriate to their ability and whether they were satisfied with their work capacity. We collected information about their highest education level, thereafter categorised as secondary education completed or lower/tertiary education completed. Interviewers gathered standardised information about impairments and comorbidities using schemes and/or decision trees: walking ability (using the Gross Motor Function Classification System (GMFCS),[31] fine motor skills (Bimanual Fine Motor Function (BFMF),[32] visual impairment (Short Set of Questions on Disability, Washington Group, difficulty or inability to see, even if wearing glasses, yes/no),[33] speaking ability (Viking Speech Scale, VSS)[34] and communication performance (Functional Communication Classification System, FCCS).[35] We assessed intellectual ability at inclusion with formal IQ testing or using an algorithm based on a set of questions to proxies.[12] The IQ was categorised as 50–69/≥70. Young adults also reported their fatigue over the past 2weeks (not at all/yes, at least several times) and seizures in the year predating interview (yes/no).

The following contextual factors were collected: population size of their area of residence (>200 000/3000–200 000/<3000 inhabitants), lifestyle (living independently, with parents, in care facilities, other) and parental highest education level (tertiary degree yes/no). We extracted nine environmental items covering transport, adapted equipment and support from the EAEQ, assessing the availability of needed physical, social and attitudinal environmental items relevant to young adults with CP. It was adapted from a similar instrument validated for children and adolescents,[36] and included some new items (eg, communication technologies) relevant to young adults.

The WHOQOL-Bref questionnaire[37] was used to measure QoL (scores of 0–100, higher scores indicating higher QoL) in four domains: physical well-being, psychological well-being, social relationships and environment.

For the subsample of individuals who had previously participated in the SPARCLE cohort as children and/or adolescents, we also had information about mainstream schooling at these targeted periods.

Statistical analysis

Analysis was carried out separately for employment and higher education statuses. We performed unconditional

logistic regressions (SAS V.9.4, SAS Institute, Cary, North Carolina, USA) to estimate ORs and 95% CI to assess the associations with personal, sociodemographic and environmental factors. We tested region, sex and age as potential confounders. Of these, we retained region for all models, and also age for models for higher education status. Each variable was analysed separately after adjustment for the potential confounders previously identified. In all models, ORs were estimated using Firth's penalised likelihood when the number of cases was ≤5. Regarding impairments and comorbidities, multivariate models were used to control for significant variables in separate analyses (p<0.20) and these models were reduced using a descending step-by-step method with p<0.05 as a criterion for statistical significance. The impairments and/or comorbidities retained in previous multivariate models were added to potential confounders for analysis of sociodemographic characteristics and environmental factors.

To estimate the impact of mainstream schooling during childhood and/or adolescence, we performed unconditional logistic regressions, adjusted for potential confounders and impairments/comorbidities previously retained, among the subsample of individuals who provided this information during their previous participation in the SPARCLE cohort.

Lastly, linear regressions adjusted for region and impairments/comorbidities were performed to explore whether being employed was associated with better QoL in physical well-being, psychological well-being, social relationships and environment domains.

Role of funding source

The funders had no role in study design, data collection, data analysis, data interpretation or writing of the publication.

RESULTS

Our cross-sectional sample included 227 young adults with CP with IQ ≥50 at inclusion. Their mean age was 24.3 years (SD 1.6 years) and male-to-female ratio was 1:3.

A large majority (78.4%) had not completed university studies. At the interview, 19.4% were still in education, 35.2% were employed and 45.4% were unemployed. Young adults who were employed mostly reported having paid work (88.8% of workers), working full-time (60.0%), given always or most of the time tasks appropriate to their ability (87.5%) and being satisfied or very satisfied with their work capacity (83.8%) (table 1).

Table 2 shows the main impairment characteristics by employment and higher education statuses. In models considering each impairment separately, individuals with more severe motor impairments (GMFCS IV–V or BFMF IV–V), with more severe communication difficulties (FCCS IV–V) and without understandable speech (VSS III–IV) were less likely to be employed or to have completed higher education. Visual impairment affected the odds of having a higher education qualification but did not significantly affect employment. On the contrary, individuals with seizures in the last year had significantly reduced odds of being employed whereas there was no difference in higher education qualification. The frequency or severity of pain and fatigue during the past 2 weeks were not associated with employment or higher education status. In the final multivariate models, individuals with the most severe gross motor function limitations (GMFCS IV–V) were significantly less likely to be employed (OR 0.23 (95% CI 0.09 to 0.56)) and had significantly less frequently completed higher education (OR 0.19 (95% CI 0.05 to 0.75)) than those with

Table 1 Sociodemographic characteristics of young adults with CP without moderate to profound intellectual impairment (n=227)— SPARCLE3—France, Germany, Italy, Portugal and Sweden, 2018–2020

	n	%
Country		
France	65	28.6
Germany	64	28.2
Italy	14	6.2
Portugal	65	28.6
Sweden	19	8.4
Sex		
Male	127	55.9
Female	100	44.1
Age (years)		
Mean (SD)	24.3	1.6
Education level		
Secondary or lower, and post-secondary non-tertiary	178	78.4
University studies (tertiary)	45	21.6
Missing	4	
Employment status		
Unemployed	103	45.4
Still in education	44	19.4
Employed	80	35.2
Remuneration		
Paid work	71	31.2
Non-paid work	3	1.3
Missing	6	
Working time		
Full-time	48	21.1
Part-time	21	9.2
Missing	11	
Given always or most of the time tasks appropriate to their ability	70	30.8
Satisfied or very satisfied with their work capacity	67	29.5

CP, cerebral palsy.

Table 2 Impairment characteristics, sociodemographic characteristics and environmental factors by employment and education status of young adults with CP without moderate to profound intellectual impairment (n=227)—SPARCLE3—France, Germany, Italy, Portugal and Sweden, 2018–2020

	Employment status*						Higher education status†					
	Unemployed (n=103)		Employed (n=80)				Secondary or lower (n=178)		Tertiary (n=45)			
	n	%	n	%	OR‡	95% CI	n	%	n	%	OR§	95% CI
Models considering each impairment separately												
GMFCS												
I–II. Independent walking ability	46	44.7	59	73.8	1.00	Ref	100	56.2	36	80.0	1.00	Ref
III. Walking ability with assistive devices	17	16.5	9	11.2	0.21	0.07 to 0.62¶	24	13.5	7	15.6	1.03	0.37 to 2.88
IV–V. No or severely limited walking ability (wheelchair)	40	38.8	12	15.0	0.12	0.05 to 0.29¶	54	30.3	2	4.4	0.12	0.03 to 0.53¶
BFMF												
I. Unilateral limitations in advanced fine motor skills	29	28.2	40	50.0	1.00	Ref	65	36.5	28	62.2	1.00	Ref
II–III. Unilateral restrictions to grasp and hold with no in-hand manipulation or worse, or bilateral restrictions in advanced fine motor skills	45	43.6	35	43.7	0.39	0.19 to 0.82¶	79	44.4	17	37.8	0.51	0.24 to 1.06
IV–V. Only grasp or worse with both hands	29	28.2	5	6.3	0.07	0.02 to 0.22¶	34	19.1	0	0.0	0.05	0.01 to 0.80¶
Visual impairment												
No	63	61.2	67	83.8	1.00	Ref	123	69.1	36	80.0	1.00	Ref
Yes, difficulty or inability to see, even if wearing glasses	40	38.8	13	16.2	0.25	0.12 to 0.55†	55	30.9	9	20.0	0.58	0.25 to 1.34
Speaking ability (Viking Speech Scale)												
I. Clearly or usually understandable	54	52.4	61	76.3	1.00	Ref	108	60.7	43	95.6	1.00	Ref
II. Imprecise but usually understandable to unfamiliar listeners	20	19.4	14	17.5	0.53	0.23 to 1.26	37	20.8	2	4.4	0.20	0.05 to 0.79¶
III–IV. No understandable speech or not usually understandable to unfamiliar listeners	29	28.2	5	6.2	0.09	0.03 to 0.27¶	33	18.5	0	0.0	0.04	0.01 to 0.70¶
FCCS												
I. Effective communication in most situations	62	60.2	71	88.8	1.00	Ref	128	71.9	45	100.0	1.00	Ref
II–III. Effective communication in most situations but does need some help	17	16.5	7	8.7	0.27	0.10 to 0.75¶	27	15.2	0	0.0	0.05	0.01 to 0.84¶
IV–V. Assistance required in most situations or communicates using undirected movement and behaviour	24	23.3	2	2.5	0.05	0.01 to 0.20¶	23	12.9	0	0.0	0.07	0.01 to 1.13
Fatigue over the last 2 weeks												
Not at all	33	33.7	23	28.7	1.00	Ref	54	31.2	12	27.7	1.00	Ref
Yes, at least several times	65	66.3	57	71.3	1.34	0.68 to 2.62	119	68.8	33	73.3	1.08	0.48 to 2.38
Missing	5		0				5		0			
Frequency of pain during the past 2 weeks												
None	36	34.9	26	32.5	1.00	Ref	62	34.8	12	26.7	1.00	Ref
Once or twice	19	18.5	20	25.0	1.63	0.69 to 3.82	12	21.4	12	26.7	1.37	0.52 to 3.31

Continued

Table 2 Continued

	Employment status*						Higher education status†					
	Unemployed (n=103)		Employed (n=80)				Secondary or lower (n=178)		Tertiary (n=45)			
	n	%	n	%	OR‡	95% CI	n	%	n	%	OR§	95% CI
Frequent	48	46.6	34	42.5	1.09	0.53 to 2.24	21	43.8	21	46.6	1.05	0.45 to 2.48
Severity of pain during the past 2 weeks												
None	35	34.3	26	32.5	1.00	Ref	61	34.7	12	26.7	1.00	Ref
Very mild to moderate	46	45.1	48	60.0	1.60	0.80 to 3.22	84	47.7	32	71.1	1.41	0.64 to 3.10
Severe or very severe	21	20.6	6	7.5	0.41	0.14 to 1.22	31	17.6	1	2.2	0.19	0.03 to 1.13
Missing	1		0				2		0			
Seizures during the last year												
No	87	84.5	76	95.0	1.00	Ref	157	88.2	45	100.0	1.00	Ref
Yes	16	15.5	4	5.0	0.20	0.06 to 0.65¶	21	11.8	0	0.0	0.12	0.01 to 2.05
Multivariate model with impairments												
GMFCS												
I–II. Independent walking ability	46	33.6	59	43.1	1.0	Ref	100	73.5	36	26.5	1.00	Ref
III. Walking ability with assistive devices	17	54.9	9	29.0	0.28	0.10 to 0.82¶	24	77.4	7	22.6	1.24	0.44 to 3.52
IV–V. No or severely limited walking ability (wheelchair)	40	67.8	12	20.3	0.23	0.09 to 0.56¶	54	96.4	2	3.6	0.19	0.05 to 0.75¶
FCCS												
I. Effective communication in most situations	62	35.6	71	40.8	1.0	Ref						
II–III. Effective communication in most situations but does need some help or have small range of messages/topics to most familiar people	17	63.0	7	25.9	0.36	0.12 to 1.05						
IV–V. Assistance required in most situations or communicates using undirected movement and behaviour	24	92.3	2	7.7	0.05	0.01 to 0.25¶						
Speaking ability (Viking Speech Scale)												
I. Clearly or usually understandable							108	71.5	43	28.5	1.00	Ref
II. Imprecise but usually understandable to unfamiliar listeners							37	94.9	2	5.1	0.21	0.05 to 0.75¶
III–IV. No understandable speech or not usually understandable to unfamiliar listeners							33	100.0	0	0.0	0.06	0.05 to 0.85¶
Models considering each sociodemographic characteristic separately												
Population size of area of residence												
>200 000	30	29.4	30	37.5	1.40	0.58 to 3.39	62	35.0	22	48.9	1.08	0.45 to 2.61
3000–200 000	56	54.9	30	37.5	1.00	Ref	81	45.8	20	44.4	1.00	Ref
<3000	16	15.7	20	25.0	2.55	0.90 to 7.18	34	19.2	3	6.7	0.35	0.09 to 1.33
Missing	1		0				1		0			

Continued

Table 2 Continued

	Employment status*						Higher education status†					
	Unemployed (n=103)		Employed (n=80)				Secondary or lower (n=178)		Tertiary (n=45)			
	n	%	n	%	OR‡	95% CI	n	%	n	%	OR§	95% CI
Lifestyle												
With parents, in care facilities or other	87	84.5	50	62.5	1.00	Ref	137	77.0	27	60.0	1.00	Ref
Independently	16	15.5	30	37.5	2.38	0.93 to 6.09	41	23.0	18	40.0	1.74	0.70 to 4.34
Higher education status												
Secondary or lower, and post-secondary non-tertiary	93	93.9	55	68.7	1.00	Ref						
University studies (tertiary)	6	6.1	25	31.3	9.37	2.87 to 30.64¶						
Missing	4		0									
Highest parental education level												
Primary and/or lower secondary	34	34.7	25	31.2	1.00	Ref	61	35.2	11	24.4	1.00	Ref
Upper secondary and/or Bachelor	41	41.8	27	33.8	0.76	0.29 to 1.97	70	40.5	8	17.8	0.72	0.23 to 2.23
Master and/or Doctorate	23	23.5	28	35.0	1.94	0.65 to 5.79	42	24.3	26	57.8	2.35	0.97 to 8.73
Missing	5		0				5		0			
Models considering each environmental factor separately												
Accessible public transport (buses/trains/taxis)												
Unmet need	19	18.4	11	13.9	1.00	Ref	31	17.5	7	15.6	1.00	Ref
Met need	84	81.6	68	86.1	0.71	0.25 to 2.08	146	82.5	38	84.4	0.79	0.25 to 2.48
Missing	0		1				1		0			
Adequate public transport (buses/trains/taxis)												
Unmet need	19	18.5	13	16.5	1.00	Ref	31	17.5	5	11.1	1.00	Ref
Met need	84	81.5	66	83.5	0.70	0.27 to 1.83	146	82.5	40	88.9	1.54	0.46 to 5.16
Missing	0		1				1		0			
Adapted vehicle												
Unmet need	14	13.6	12	15.0	1.00	Ref	29	16.3	9	20.0	1.00	Ref
Met need	89	86.4	68	85.0	0.60	0.21 to 1.74	149	83.7	36	80.0	1.07	0.39 to 2.89
Accessible car parking in places where need to park												
Unmet need	32	31.4	12	15.0	1.00	Ref	42	23.7	10	22.2	1.00	Ref
Met need	70	68.6	68	85.0	3.30	1.28 to 8.55¶	135	76.3	35	77.8	0.80	0.30 to 2.15
Missing	1		0				1		0			
Grants for travel												
Unmet need	35	34.0	13	16.3	1.00	Ref	43	24.2	8	17.8	1.00	Ref
Met need	68	66.0	67	83.8	1.49	0.61 to 3.63	135	75.8	37	82.2	1.16	0.43 to 3.12

Continued

Table 2 Continued

	Employment status*						Higher education status†					
	Unemployed (n=103)		Employed (n=80)				Secondary or lower (n=178)		Tertiary (n=45)			
	n	%	n	%	OR‡	95% CI	n	%	n	%	OR§	95% CI
Information about education/employment												
Unmet need	50	51.0	21	26.3	1.00	Ref	67	38.7	9	20.0	1.00	Ref
Met need	48	49.0	59	73.8	1.50	0.67 to 3.40	106	61.3	36	80.0	1.92	0.75 to 4.91
Missing	5		0				5		0			
Adapted equipment												
Unmet need	3	3.0	4	5.0	1.00	Ref	7	4.0	2	4.4	1.00	Ref
Met need	96	97.0	76	95.0	0.60	0.09 to 3.90	167	96.0	43	95.6	0.98	0.13 to 7.54
Missing	4		0				4		0			
Encouragement from family/friends												
Unmet need	5	4.9	6	7.6	1.00	Ref	9	5.1	3	6.7	1.00	Ref
Met need	98	95.1	73	92.4	0.42	0.09 to 1.97	168	94.9	42	93.3	0.93	0.19 to 4.53
Missing	0		1				1		0			
Emotional support from family/friends												
Unmet need	3	2.9	2	2.5	1.00	Ref	7	4.0	0	0.0	1.00	Ref
Met need	100	97.1	77	97.5	0.84	0.17 to 4.19	170	96.0	45	100.0	–	–
Missing	0		1				1		0			

*Young adults who were still in education at interview (n=44) were excluded from analysis.
†Young adults who did not complete information about higher education status (n=4) were excluded from analysis.
‡All unconditional logistic regression models were adjusted for region. Models considering each sociodemographic characteristic and each environmental factors separately were also adjusted for GMFCS and FCCS.
§All unconditional logistic regression models were adjusted for region and age. Models considering each sociodemographic characteristic and each environmental factors separately were also adjusted for GMFCS and speaking ability.
¶ 95% CI excluding 1.00.
BFMF, Bimanual Fine Motor Function; CI, Confidence interval; CP, cerebral palsy; FCCS, Functional Communication Classification System; GMFCS, Gross Motor Function Classification System; OR, Odds Ratio.

mild or moderate gross motor restrictions (GMFCS I–II). Similarly, the odds of being employed were significantly reduced for individuals with GMFCS III (OR 0.28 (95% CI 0.10 to 0.82)) and with communication difficulties (FCCS IV–V, OR 0.05 (95% CI 0.01 to 0.25)). Having imprecise speech (VSS II) or having no understandable speech (VSS III–IV) were associated with reduced odds of completing higher education (OR 0.21 (95% CI 0.05 to 0.75) and (OR 0.02 (95% CI 0.05 to 0.85)), respectively).

Whatever the severity of their motor impairment and communication difficulties, young adults with CP who completed higher education were more likely to be employed (OR 9.37 (95% CI 2.87 to 30.64)). We observed no differences in employment or higher education status according to population size of the area of residence, lifestyle or parental education level (table 2).

For individuals living in an environment that met their needs in terms of accessibility to car parking, the odds of being employed (OR 3.30 (95% CI 1.28 to 8.55)) were significantly higher compared with those with unmet needs. We observed no differences in employment or higher education status for all other environmental characteristics, whether physical, social or attitudinal needs (table 2).

In the subsample of 93 young adults who were not still in education and who had previously participated in the SPARCLE cohort, we found that mainstream schooling during childhood significantly increased the odds of being employed in young adulthood (OR 11.71 (95% CI 1.04 to 131.66)). The effect was greater when mainstream schooling was continued during adolescence (OR 16.14 (95% CI 1.33 to 195.12)), independently of the severity of motor and communication impairments (table 3).

In the overall sample, compared with the unemployed, young adults who were employed reported significantly higher QoL in the physical well-being domain by 8.55 points (95% CI 3.19 to 13.91) and in the psychological well-being domain by 7.98 points (95% CI 2.88 to 13.08) (table 4).

DISCUSSION

In accordance with the Convention on the Rights of Persons with Disabilities[38] promoting full participation in socially expected roles, we explored higher education status and employment status as markers of integration in young adulthood. We showed that, overall, 45.4% of young adults with CP and an IQ ≥50 were neither in higher education nor in employment. Of those who were employed (35.2%), more than 4 in 5 reported being paid, being given tasks appropriate to their abilities, or being satisfied with their work capacity. The likelihood of employment was significantly reduced (by more than 75%) for young people with severe gross motor limitations or severe communication difficulties compared with less severely impaired participants. The probability of obtaining a higher education degree was reduced by a factor of 0.19 for young people with severe gross motor impairments and by 0.02 for those with imprecise or non-understandable speech. Having a higher education qualification and having attended a mainstream school during childhood, or continued mainstream education until adolescence were found to be powerful levers for access to employment (12-fold and 16-fold increases in the odds of being employed, respectively). Except for the accessibility of car parking when needed, none of the environmental factors studied significantly influenced employment or higher education status, after adjustment for

Table 3 Inclusion or insertion in mainstream education during childhood and/or adolescence by employment and education status of young adults with CP without moderate to profound intellectual impairment (n=113)—SPARCLE3—France, Germany, Italy and Sweden, 2018–2020

	Employment status*						Higher education status					
	Unemployed (n=42)		Employed (n=51)				Secondary or lower (n=90)		Tertiary (n=23)			
	n	%	n	%	OR†	95% CI	n	%	n	%	OR‡	95% CI
Inclusion or insertion in mainstream school in childhood or in adolescence												
No	9	21.4	11	21.6	1.00	Ref	20	22.2	0	0.0	1.00	Ref
Yes	33	78.6	40	78.4	9.13	0.84 to 99.46	70	77.8	23	100.0	5.79	0.37 to 90.66
In childhood	29	69.0	40	78.4	11.71	1.04 to 131.66§	64	71.1	23	100.0	6.26	0.41 to 94.52
Only in childhood	8	19.0	4	7.9	–	–	12	13.3	2	8.7	2.89	0.15 to 56.77
In adolescence	25	59.5	36	70.6	8.68	0.79 to 95.90	58	64.4	21	91.3	8.71	0.52 to 146.28
Only in childhood	4	9.5	0	0.0	–	–	6	6.7	0	0.0	–	–
In childhood and adolescence	21	50.0	36	70.6	16.14	1.33 to 195.12§	52	57.8	21	91.3	9.82	0.58 to 165.35

*Young adults who were still in education at interview (n=20) were excluded from analysis.
†All unconditional logistic regression models were adjusted for region, GMFCS and FCCS.
‡All unconditional logistic regression models were adjusted for region, age, GMFCS and speaking ability.
§95% CI excluding 1.00.
CI, Confidence Interval; CP, cerebral palsy; FCCS, Functional Communication Classification System; GMFCS, Gross Motor Function Classification System; OR, Odds Ratio.

Table 4 Distribution and variation of QoL by employment status of young adults with CP without moderate to profound intellectual impairment (n=227)—SPARCLE3—France, Germany, Italy, Portugal and Sweden, 2018–2020

	Physical well-being	Psychological well-being	Social relationships	Environment
Employment status				
Unemployed				
n	103	100	103	103
Mean (SD)	62.4 (20.4)	67.8 (16.7)	68.6 (23.0)	72.1 (14.7)
(min–max)	(10.7–96.42)	(16.7–100.0)	(8.3–100.0)	(31.2–100.0)
Employed				
n	80	80	80	80
Mean (SD)	75.0 (14.6)	75.1 (15.6)	72.2 (19.1)	76.2 (14.3)
(min–max)	(28.6–84.4)	(37.5–100.0)	(16.7–100.0)	(43.7–100.0)
Difference in QoL scores*				
β (95% CI)	8.55 (3.19 to 13.91)†	7.98 (2.88 to 13.08)†	0.84 (–5.74 to 7.43)	3.33 (–1.35 to 8.02)

*All linear regression models were adjusted for region and GMFCS and FCCS. β coefficients show the average difference in quality of life by employment status (with unemployed as reference).
†95% CI excluding zero.
CI, Confidence Interval; CP, cerebral palsy; FCCS, Functional Communication Classification System; GMFCS, Gross Motor Function Classification System; QoL, quality of life.

impairments. Young adults who were employed reported significantly higher physical and psychological well-being than those without employment.

Based on eight studies, the meta-analysis by van Gorp *et al*[25] reported a mean weighted rate of completed higher education of 18.2% (95% CI 10.6 to 27.2), similar to our findings. The authors identified four studies of adults with and without intellectual disability that reported an employment rate with a mean weighted proportion of 55.5% (95% CI 31.5 to 78.3), higher than that of our study. This discrepancy may be due to differences in the populations studied. The exclusion criteria of intellectual disability applied in these studies used different definitions (such as 'no learning deficiency' or 'no cognitive impairment preventing understanding the study instructions'), or a stricter criterion (IQ >70), which may have selected individuals who were more likely to be employed than those in our study. Also, with one exception, all these studies included a wider age range, making comparison with our sample difficult. Moreover, given that our sample was younger than those in the other studies, a substantial proportion was still in education (19.4%). Most of these young adults can be expected to be eligible for employment, bringing the proportion of employment closer to that found in the meta-analysis. This hypothesis may be supported by the fact that young adults who were still in education did not differ significantly in any of the factors studied from those who were employed, except that they were younger (online supplemental table 1). While the observed employment rate remained low, those who worked generally reported satisfactory employment conditions. Nevertheless, further studies comparing them with their peers of the same age in the general population will be needed to position their working conditions more accurately.

As impairments were the main barriers to the participation of people with disabilities identified so far, we examined them closely and found that severe motor and communication impairments were the most detrimental factors to achieving higher education or accessing employment. To our knowledge, these findings in relation to higher education levels have never been studied and should therefore be replicated. Regarding employment, three previous studies[22 24 26] support our finding that severe motor impairment was strongly associated with reduced employment rates. Among them, a recent Swedish cross-sectional registry-based study[24] also found that reduced communication ability was significantly associated with a lower employment rate. It should be noted that motor and communication impairments, when severe, independently reduced access to employment but that the effects were mediated by higher educational level, as was also observed in a Dutch cross-sectional study.[39] The role of comorbidities is less clear. The association between seizures and employment reported by Michelsen *et al*[22] appeared non-significant after the analysis was adjusted on impairments. Lastly, as suggested by Pettersson and Rodby-Bousquet,[24] we performed the analysis with fatigue, which was experienced by more than two-thirds of respondents, but we found no association.

An Australian study[40] investigated the role of environmental factors in education and employment in young adults with CP aged 18–25 years. For education and employment, study participants reported that the lack of transport access (35.8% and 42.2%, respectively) and the lack of family help or assistance (21.5% and 25.3%, respectively) somewhat or greatly affected their participation. Our study adds information by being the first to examine associations between environmental factors and higher education and

employment. Of the 61 EAEQ items, we selected a priori nine items for their relevance in potentially modifying the level of education achieved or the employment status,[41] with the hypothesis that unmet environmental needs may act as barriers. We found no significant association between these two outcomes, except for access to car parking which seemed to increase the employment rate. Another option would have been to consider the environment as a whole, hypothesising that a combination of barriers may have an impact. The fact that we did not observe any association does not minimise the role of an appropriate environment in increasing the social participation of young adults with CP. It is interesting to note that six of the nine environmental factors studied were largely met when needed (>80%) regardless of higher education completion or employment status. This encouraging observation suggests that other meaningful daily activities (such as going to an activity centre or meeting friends) may also be more frequent.

Unsurprisingly, and in line with the OECD observations for the general population,[42] we found that completion of a higher education degree was an important determinant of employment among young adults with CP. Our findings also suggested that the role of education may be determinant from an early age and may be stronger when the social inclusion process is maintained in adolescence. However, due to the small sample size and the fact that our mainstream school data (collected once in childhood and once in adolescence) was not intended to capture the entire school career, this finding should be interpreted with caution.

The perceptual and subjective aspects of QoL seem to us to be relevant in understanding the role of employment, as effective inclusion, in the daily life of young adults with CP. Whatever their region, motor functions or communication ability, we observed that individuals with CP who were employed had a significantly higher mean QoL score in the physical and psychological well-being domains. This highly positive finding supports the hypothesis that full and successful inclusion in society may help to improve the perception that the person with CP has of his or her position in life. Nevertheless, being employed did not increase their satisfaction with social relationships, although work might have been expected to be a factor in favour of social relations. In a previous study,[43] we hypothesised that factors associated with lower QoL in the social relationships domain may indirectly reflect limited access to employment. Our current study did not support this hypothesis. Finally, to our knowledge, this cross-sectional analysis is the first of its kind in adults with CP and should be replicated in further studies, particularly those able to establish the temporal relationship between employment and QoL, such as cohort studies.

In this cross-sectional study, we identified cases from population-based registries in five European regions and from several independent sources in two additional regions using the same definition of CP, which limited case selection and classification errors. Nevertheless, we cannot document to what extent our sample is representative of the CP population of the countries studied, due to the regional coverage of registries and the impossibility of comparing the distribution we observed with external sources. Our results should therefore be interpreted with caution in terms of generalisability. We can only compare the sample characteristics with those of previous studies. For individuals who have participated in the SPARCLE cohort since they were children and/or adolescents, previous analyses[43] showed a significant increase in dropout rate among young adults with at least one parent who did not complete secondary education. This differential attrition might overestimate the distribution of employment and higher education. The effect on observed distribution of intentional overrepresentation of the most severe phenotypes is difficult to quantify because we excluded from our sample young adults with an IQ <50 or equivalent. Overall, we collected data with validated measurement tools during standardised interviews and there were very few missing data. Despite the small sample size of the subgroup of individuals longitudinally followed and limited data on mainstream schooling during youth, we found a major and significant effect of mainstream schooling on employment status. On this point, as on others in this paper, the data should be replicated.

In conclusion, the employment situation of young adults with CP can still be improved, but our findings encourage the implementation of inclusive policies from an early age. For people with CP with severe motor and communication impairments, the use of modern, sophisticated, intelligent technology for communication and mobility covered by the educational, disability services or healthcare services may greatly enhance school and work careers.

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