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RESEARCH PAPER

Childhood factors predict participation of young adults with cerebral palsy in domestic life and interpersonal relationships: a prospective cohort study

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ABSTRACT

Purpose: To determine childhood predictors of participation in domestic life and interpersonal relationships of young adults with cerebral palsy (CP).

Materials and methods: This 13-year follow-up of an existing cohort (baseline age 9–13 years) included 67 young adults with CP (age 21–27 years). The Vineland adaptive behavior scales (VABS) and Life Habits questionnaire were used to assess attendance and difficulty in participation in domestic life and interpersonal relationships. Baseline factors were categorised according to the international classification of functioning, disability, and health. Stepwise multiple linear regression analyses determined significant predictors ($p < 0.05$).

Results: Lower manual ability, intellectual disability (ID), epilepsy and lower motor capacity predicted decreased future participation in domestic life, and/or interpersonal relationships (explained variance $R^2 = 67–87\%$), whereas no association was found with environmental and personal factors. Extending models with baseline fine motor skills, communication, and interpersonal relationships increased R^2 to 79–90%.

Conclusions: Childhood factors account for 79–90% of the variation in young adult participation in domestic life and interpersonal relationships of individuals with CP. Children with limited motor capacity, low manual ability, ID, or epilepsy are at risk for restrictions in participation in young adulthood. Addressing fine motor, communication, and social skills in paediatric rehabilitation might promote young adult participation.

➤ IMPLICATIONS FOR REHABILITATION

- Childhood risk factors for limited participation in domestic life and interpersonal relationships as a young adult with CP are ID, epilepsy, low manual ability, low motor capacity, and low activity & participation levels.
- In line with current practice, this study confirms the importance of addressing gross and fine motor skills in children with CP for their future participation in domestic life.
- In addition, results suggest that addressing communication and social skills during paediatric rehabilitation may optimise future participation in interpersonal relationships.

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Cerebral palsy; young adult; child; predictors; participation; interpersonal relationships; domestic life

Introduction

Cerebral palsy (CP) describes a group of permanent disorders of movement and posture, attributed to non-progressive disturbances in the developing foetal or infant brain, causing activity limitations [1]. The International Classification of Functioning, Disability, and Health (ICF) defines participation as "involvement in a life situation" and describes its relation with an individual's health status, body functions & structures, ability to perform activities, and also with environmental and personal factors [2]. For activities and participation, the ICF describes the qualifier capacity as "what one can do in a standardized environment", and the qualifier performance as "what one actually does in their current environment" [2]. Since most children with CP now survive into adulthood, and young adults with CP are known to be restricted in their participation, insight is required to help early identification of individuals at increased risk of future restrictions in participation [3–5].

Among young adults with CP, a large proportion experiences difficulty in participation, particularly in domestic life [6]. Moreover, for domestic life and interpersonal relationships, these proportions increase from age 16 years onward [6]. Participation

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in *domestic life* includes activities in/around the protected environment of one's home, e.g., preparing meals and doing housework [2]. Participation in *interpersonal relationships* includes socially appropriate interactions with others in various contexts, e.g., maintaining both formal and intimate relationships [2]. Because of the different contexts and different types of activities in these domains of participation, the predictors of these two domains are expected to vary. Therefore, and also because of increasing difficulties in both domains from teenage years into adulthood, these two are of particular interest.

Previously, we reported on cross-sectional associations between participation and CP-related characteristics, body functions and environmental and personal factors that were explored in youth and young adults with CP [5,7–9]. These (and other) studies demonstrated that individuals who were more severely functionally affected were more restricted in both their domestic life and interpersonal relationships [5,8–10]. In addition, these studies revealed that different factors are associated with either domestic life or interpersonal relationships. For example, for domestic life, adequate adaptations in the home environment were related to higher participation [10]. For interpersonal relationships, restricted participation was associated with having epilepsy and several environmental (e.g., less favourable attitudes of family and friends) and personal factors (e.g., behaviour problems) [7,8,10]. To enable clinicians to timely optimise treatment, longitudinal studies are needed that provide information on factors predicting future participation, in addition to the above-mentioned cross-sectional associations.

Until now, for individuals with CP, the predictors of participation have only been studied longitudinally among youth and over a relatively short period of time [11,12]. The baseline level of participation was shown to be the most important predictor of participation five years later [11]. Also, being more affected by CP (e.g., by having poorer walking ability or intellectual disability [ID]) and psychological problems in childhood predicted more limitations in participation in domestic life five years later [11]. For domestic life, CP-related characteristics explained a larger part of future participation compared to interpersonal relationships [11]. Furthermore, environmental factors (e.g., parental stress) predicted poorer future participation in interpersonal relationships, but not in domestic life [11,12]. However, it remains unclear whether childhood factors also predict participation in young adulthood.

Insight into childhood factors predicting future participation as young adults may identify: i) which individuals with CP are at risk for restricted participation, and ii) provide information on modifiable factors that can be addressed in paediatric rehabilitation. Therefore, this study aimed to determine whether childhood factors predict participation in domestic life and in interpersonal relationships of young adults with CP.

Material and methods

Design

This study describes the 13-year follow-up of the PERRIN (Paediatric Rehabilitation Research in the Netherlands) 9–16 cohort, with previous yearly assessments over the course of 3 years [8].

Participants

At baseline, 244 children with CP who were 9, 11, or 13 years of age were identified by rehabilitation centres, special education institutions for physically and mentally disabled children, and outpatient clinics of rehabilitation medicine departments in the northwest region of the Netherlands. These children and their parents were sent an information letter about the 3-year longitudinal study and invited to participate. Finally, 110 children and their parents returned the informed consent form and participated in the PERRIN 9–16 cohort. The study was approved by all regional medical ethics committees.

Participants of the PERRIN 9–16 cohort ($n = 110$) were invited for a 13-year follow-up (PERRIN DECADE) at age 21–27 years, with the exception of one deceased participant, and another three were excluded since they had a diagnosis other than CP that affected their motor functioning. Two mailings of information letters and a telephone call were carried out, and in case of no response, consecutively a telephone call or additional mailing was sent. In brief, participants had a clinical diagnosis of CP without additional disorders affecting motor functioning, and participants and their parents or caregivers were able to participate in face-to-face interviews in Dutch. The PERRIN DECADE study was approved by the Medical Ethical Committee of the VU University Medical Center, Amsterdam.

Procedure

At the 13-year follow-up, participants and/or their caregivers (caregivers were only present for interviews with individuals with ID) were interviewed regarding participation in interpersonal relationships and domestic life at home or another location they selected. The Vineland adaptive behavior scale second edition survey version (Vine-II) and the assessment of life habits 3.1 (Life-H) were used, which evaluate different constructs of participation. Additionally, at 13-year follow-up an online questionnaire regarding the participant's living and civic status was completed by participants or, in case the participant had ID, their caregiver. Questions addressed participants' housing situation, housing type, and intimate relationships. Baseline factors were previously collected from the child's caregiver, using various instruments and questionnaires (see below).

Materials and instruments

Domestic life and interpersonal relationships in young adulthood

Vineland adaptive behavior scale second edition survey version (Vine-II). The Vine-II assesses whether or not activities are performed in daily life areas, which addresses an aspect of attendance of participation. Therefore, Vine-II scores are further indicated as participation attendance. The Vine-II covers domains of communication, daily activity, socialisation, and motor skills. For this study, the participation subdomains of "domestic daily living skills" and "interpersonal relationships" were used. Items were scored as never performed (0), sometimes or partially performed (1), or usually or habitually performed (2). Performance could include the use of assistive devices or adaptations, if individuals used these in their usual functioning. The Vine-II has high intra-rater reliability and moderate inter-rater reliability and is validated in healthy children and adults, individuals with ID, and children with hearing or visual impairment [13]. Individuals with a score lower than one standard deviation (SD) below the mean reference value were considered to function below an adequate level according to their age.

Assessment of life habits 3.1 (Life-H). The Life-H questionnaire 3.1 assesses participation performance, further qualified by experienced difficulty and assistance required, with performance in 12 domains of daily activities and social roles. For this study, the domain scores of "housing" and "interpersonal relationships" were

used and are further reported as difficulty in participation in these domains. For each applicable item, difficulty was scored as "no difficulty", "some difficulty", "accomplished by a proxy", or "not accomplished". Assistance was scored as "no assistance", "use of assistive device", "adaptation", and/or "with human assistance" (dependent functioning). From both scores, an item score was derived, from which a sum score of applicable items was calculated for each domain (range 0–10) [14]. A domain score <8.89 reflects participation with difficulty. The Life-H was developed for individuals with disabilities, has good intra- and inter-rater reliability and good discriminant, and construct validity in adults with spinal cord injury and stroke [15,16].

Baseline factors

Factors assessed at baseline were categorised according to the ICF components addressing health condition, body functions and structures, motor capacity, activity & participation, environmental factors, and personal factors.

Health condition included the CP-related classifications gross motor function classification system (GMFCS), manual ability classification system (MACS) and CP subtype. GMFCS and MACS are classifications for functional severity ranging from I (highest functional level) to V [17,18]. Since no baseline data of MACS level were available, the 3-year follow-up assessment was used. To reduce the number of independent variables, the GMFCS level was subdivided in three categories: levels I and II, III and IV, and level V. MACS level was dichotomised: levels I and II *versus* levels III–V. CP subtype was categorised in spastic (both unilateral and bilateral) or non-spastic CP (ataxic, dyskinetic, or mixed subtype) [19].

Body functions and structures included ID (following a special education programme for children with ID, no/yes), epilepsy (more than one seizure during the previous two years or using antiepileptic drugs, no/yes), visual impairment (use of visual aids, no/yes), hearing impairment (use of a hearing device, no/yes), and speech problems (using the item "speech problems" in the child behavior checklist (CBCL), no/somewhat or very true) [20].

Motor capacity was assessed with the 66-item gross motor function measure-66 (GMFM-66), a standardised observational instrument developed to assess gross motor skills of children with CP in a standardised test situation. The items were scored on a 4-point scale and analysed with the Gross Motor Ability Estimator to obtain a ratio scale GMFM-66 score [21].

Activity & participation further included the baseline performance of motor skills (gross and fine), communication (receptive, expressive, and written), daily living skills (personal, domestic, and community) and socialisation (interpersonal relationships, play & leisure, and coping skills), assessed with the corresponding subdomains of the Vineland adaptive behavior scale (VABS) survey. The VABS is the preceding version of the Vine-II, which was not available at the time of the baseline assessments. VABS items are scored as never performed (0), sometimes or partially performed (1), or usually or habitually performed (2), and which are summed for each subdomain. The VABS is a reliable and valid instrument to assess activity and participation performance of children by means of a semi-structured interview and is validated for use in individuals with ID and in children with hearing or visual impairments [22].

Environmental factors included housing type (regular/adjusted), the child's type of education (regular/special), the number of siblings (0 or 1/$\geq$2), parental level of education (low/intermediate: upper secondary vocational education and lower, or high: secondary non-vocational higher education and university), marital status of parents (single/married or with partner), and parental stress and support. Parental stress and support were measured with a questionnaire based on the Dutch version of Moos' Life Stressors and Social Resources Inventory. Items were scored on a 4-point scale, with higher scores indicating more stress and less social resources. Mean domain scores were calculated for relational stress and social resources (items on interpersonal relationships) and situational stress and resources (items on financial and material resources, and life events) [23].

Personal factors included gender, age, nationality (Dutch or other), behavioural problems, and perceived self-competence. Behavioural problems were assessed with the six domains of the CBCL, depression, anxiety, withdrawal, somatisation, delinquency, and aggression. Items reflect behavioural problems, and are scored as 0 = not applicable, 1 = somewhat applicable, and 2 = applicable. Two sum scores were calculated: 1) for internalising behaviour (depression, anxiety, withdrawal, and somatisation) and 2) for externalising behaviour (delinquency and aggression). The CBCL has good reliability in children with developmental delays [20]. Self-competence was assessed with Harter's Social Perception Profile for children (SPPC), adjusted for use in children with CP. The SPPC has six scales: scholastic competence, social acceptance, athletic competence, physical appearance, global self-worth, and motor competence. Each scale score is the mean of items that are scored on a four-point scale [24,25].

Statistical analysis

Starting at baseline, from the PERRIN 9–16 cohort, four annual observations were available for motor capacity (GMFM-66) and activity & participation (VABS). To reduce the influence of measurement error, all four observations were used to model baseline scores that were used in the analyses. To model baseline scores, linear mixed model analyses were used with age as covariate, a random intercept to allow individual estimation of the baseline value, and (if applicable) a random slope for age. For baseline factors and for participant characteristics at the 13-year follow-up, descriptive statistics were computed.

To determine which baseline factors best predict participation in domestic life and interpersonal relationships at 13-year follow-up, stepwise multiple linear regression analyses were performed. Dependent variables were the (sub)domain scores of domestic life and interpersonal relationships of the Vine-II and Life-H. For each ICF component, a forward selection procedure was conducted until no additional factor contributed with a cut-off p values <0.1. Then, final prediction models were determined, again using a forward selection procedure (cut-off p values <0.05), including only the selected factors of the ICF components CP-related characteristics, body functions, motor capacity and environmental, and personal factors. In an additional step, we examined whether the childhood level of activity and participation performance provided additional value to these final prediction models. Therefore, these extended models were determined by adding childhood activity and participation factors (one by one) to the final prediction models, to investigate whether possible modifiable factors could be identified. If more than one factor made a significant contribution, the strongest ones were selected using a forward selection procedure (cut-off p values <0.05).

To check for potential influence of dropouts the baseline distribution of sex, ID, GMFCS level and type of CP of individuals who dropped out ($n = 40$) were compared to those included ($n = 67$) using a chi-square test. All analyses were done using SPSS version 22 for Windows (IBM SPSS Statistics, Armonk, NY).

Results

Participants

Of the 106 invited PERRIN 9–16 participants (existing cohort), 22 declined and 17 did not respond. Thus, the 13-year follow-up included 67 young adults with CP aged 21–27 years. Table 1 presents the participants' characteristics at the 13-year follow-up and characteristics of individuals who dropped out ($n = 40$). Dropout was not selective regarding sex, ID, CP subtype, and GMFCS level at baseline.

Participation in domestic life and interpersonal relationships

On average, for domestic life, young adults with CP scored 30.8 (SD 17.5) on the Vine-II, with 73% of individuals performing below an adequate level according to their age. Difficulty was experienced by 66% of individuals, with a mean score of 7.2 (SD 2.4) on the Life-H. For interpersonal relationships, young adults with CP on average scored 65.5 (SD 14.9) on the Vine-II, with 64% of individuals performing below an adequate level according to their age. Difficulty was experienced by 33% of individuals, with a mean score of 8.6 (2.0) on the Life-H.

Table 1. Characteristics of participants at 13-year follow-up and of non-participants.

	Participants *n* (%)	Non-participants *n* (%)
Gender		
Male/female	45/22 (67/33)	22/18 (55/45)
Age in years: mean (SD); min–max	24.6 (1.6); 21.6–27.4	na
GMFCS[a]		
I	30 (45)	19 (48)
II	7 (10)	7 (18)
III	8 (12)	5 (13)
IV	9 (13)	4 (10)
V	13 (19)	5 (13)
MACS[b]		
I	26 (39)	13 (45)
II	22 (33)	11 (38)
III	7 (10)	2 (7)
IV	7 (10)	3 (10)
V	5 (7)	0
		Missing: 11
Type of CP		
Spastic	52 (78)	34 (85)
Unilateral	21	16
Bilateral	31	18
Dyskinetic	3 (5)	1 (3)
Ataxic	3 (5)	1 (3)
Mixed	9 (13)	4 (10)
ID		
No/yes	46/21 (69/31)	29/11 (73/28)
Housing situation		na
with parents	36 (55)	
alone	17 (26)	
with partner	2 (3)	
other	10 (15)	
	Missing[c]: 2	
Housing type		na
Regular housing	34 (52)	
Adjusted housing	17 (26)	
Assisted housing	14 (22)	
	Missing[c]: 2	
Ever in a romantic relationship		na
Yes/no	34/28 (55/45)	
	Missing[c]: 5	

[a]GMFCS data were assessed at baseline and considered constant for analysis.
[b]MACS data were assessed at the 3-year follow-up or at the 13-year follow-up in case of missing values ($n = 3$) and considered constant for analysis.
[c]Missing: Two participants did not complete the online questionnaire. Additionally, three participants chose not to answer the question on romantic relationships.
na: not available, since this data was collected at the 13-year follow-up.
SD: standard deviation; GMFCS: gross motor function classification system; MACS: manual ability classification system; CP: cerebral palsy; ID: intellectual disability.

Included factors

Table 2 presents the (modelled) baseline factors. Within each ICF component, the significant predictors are presented for each of the four participation outcome measures.

Predictors domestic life

The final prediction models for attendance (Vine-II) and difficulty (Life-H) in participation in domestic life are presented in Table 3 (explained variance 87 and 79%, respectively). Having ID or a lower GMFM-66 score predicted lower attendance and more difficulty in participation in domestic life in young adulthood. Compared to participants in MACS I-II, individuals in MACS III-V had lower future participation attendance (but not more difficulty) in domestic life.

Extending the attendance model of domestic life with baseline activity and participation did not improve the model. For difficulty, the extended model included the baseline performance of fine motor skills and receptive communication; these factors added 7.4% of the explained variance compared to the prediction model without activity and participation.

Predictors interpersonal relationships

The final prediction models for attendance (Vine-II) and difficulty (Life-H) in participation in interpersonal relationships are also presented in Table 3 (explained variance 74 and 67%, respectively). Having ID or epilepsy predicted lower attendance and more difficulty in participation in interpersonal relationships in young adulthood. Those in MACS III-IV compared to individuals in MACS I-II had lower future participation attendance (but not difficulty) in interpersonal relationships. In addition, a lower baseline value of the GMFM-66 predicted more difficulty.

For attendance in interpersonal relationships the extended model included baseline expressive communication, and for difficulty the extended model included baseline interpersonal relationships; both these latter factors added 16.5 and 11.9%, respectively, of the explained variance compared to the prediction models without activity & participation. In these extended models, epilepsy (for attendance), or ID (for difficulty) were no longer significant predictors.

Discussion

This study explored childhood factors of individuals with CP that may predict future participation in domestic life and interpersonal relationships in adulthood. It was found that childhood factors explained a large part of the variance in young adult participation, i.e., up to 90%. Also, individuals with low motor capacity, low manual ability, and ID were at increased risk for lower levels of future participation in domestic life. Similarly, future participation in interpersonal relationships was lower for these same individuals and, additionally, for those with epilepsy. However, in these models, no environmental or personal factors were identified as significant predictors. Extending the models with childhood activity and participation levels substantially improved the models for future interpersonal relationships.

Table 2. Possible predictive factors by ICF component at baseline.

		Domestic life		Interpersonal relationships	
	Total $n = 67$, age at baseline: 9-13 years	Attendance **(Vine-II)**	Difficulty (Life-H)	Attendance **(Vine-II)**	Difficulty (Life-H)
CP-related characteristics (health condition)	*n* (%)	Selected predictors of cluster, β (SE); R^2		Selected predictors of cluster, β (SE); R^2	
GMFCS in 3 categories					
I + II	37 (55)	ref category	ref category	ref category	ref category
III + IV	17 (25)	−16.66 (2.69)***	−1.80 (0.39)***	−4.99 (3.31)	−0.56 (0.42)
V	13 (19)	−27.62 (4.12)***	−5.26 (0.43)***	−19.45 (5.07)***	−3.9 (0.49)***
MACS in 2 categories					
I + II	48 (72)	ref category		ref category	
III + IV + V	19 (28)	−11.66 (3.46)***		−8.45 (4.26)*	
Type of CP (spastic/other)	52/15 (78/22)				0.92 (0.45)**
		R^2: 76%	R^2: 70%	R^2: 50%	R^2: 51%
Body functions and structures	*n* (%)	Selected predictors of cluster, β (SE); R^2		Selected predictors of cluster, β (SE); R^2	
ID (no/yes)	46/21 (69/31)	−17.88 (3.81)***	−2.92 (0.52)***	−18.50 (2.74)***	−1.97 (0.37)***
Epilepsy (no/yes)	61/6 (91/9)	−11.44 (5.27)**	−1.42 (0.74)*	−17.30 (4.45)***	−3.19 (0.59)***
Visual impairment (no/yes)	53/14 (79/21)	−15.00 (4.07)***	−1.35 (0.57); 0.021**		
Hearing impairment (no/yes)	64/3 (96/4)				
Speech problems (item 79 of CBCL) (no/yes)	35/31 (52/46)				
	missing: 1 (1)	R^2: 62%	R^2: 61%	R^2: 59%	R^2: 58%
Motor capacity	mean (SD); min-max	Selected predictors of cluster, β (SE); R^2		Selected predictors of cluster, β (SE); R^2	
Gross motor capacity (GMFM-66) *(66 items, range 0-100)*	64.73 (28.28); 3.66 to 99.45	0.55 (0.04)***	0.07 (0.01)***	0.35 (0.05)***	0.05 (0.01)***
		R^2: 79.7%	R^2: 71%	R^2: 44.3%	R^2: 40.6%
Activities and participation	mean (SD); min-max	Selected predictors of cluster, β (SE); R^2		Selected predictors of cluster, β (SE); R^2	
VABS Motor skills					
– Gross *(20 items, range 0-40)*	24.23 (12.45); 2.07 to 39.23	0.82 (0.14)***	0.06 (0.02)***		
– Fine *(16 items, range 0-32)*	23.73 (10.23); 0.10 to 31.70	0.62 (0.17)***	0.14 (0.03)***	1.13 (0.11)***	0.14 (0.02)***
		R^2: 81%	R^2: 77%	R^2: 60%	R^2: 50.4%
VABS Communication					
– Receptive *(13 items, range 0-26)*	24.42 (3.94); 2.13 to 25.94		0.19 (0.05)***		0.31 (0.04)***
– Expressive *(31 items, range 0-62)*	53.24 (14.03); 2.45 to 60.50			0.83 (0.07)***	
– Written *(23 items, range: 0-46)*	22.66 (12.84); 0.06 to 40.39	1.14 (0.09)***	0.12 (0.02)***	0.23 (0.07)***	0.05 (0.01)***
		R^2: 70%	R^2: 70%	R^2: 87%	R^2: 71%
VABS Daily living skills					
– Personal *(39 items, range 0-78)*	55.36 (21.31); -0.30 to 75.88	0.75 (0.04)***	0.10 (0.03)***		0.07 (0.01)***
– Domestic *(21 items, range 0-42)*	14.34 (6.98); 0.61 to 25.02				
– Community *(32 items, range 0-64)*	30.55 (13.99); -0.55 to 47.19		0.04 (0.02)**	0.91 (0.07)***	
		82%	R^2: 82%	R^2: 73%	R^2: 57%
VABS Socialization					
– Interpersonal relationships *(28 items, range: 0-56)*	42.08 (7.79); 11.21 to 49.01			0.63 (0.35)*	0.10 (0.05)**
– Play and leisure *(20 items, range: 0-40)*	29.44 (7.14); 1.98 to 36.14		0.14 (0.06)**	0.74 (0.34)**	0.13 (0.05)**
– Coping (*18 items, range: 0-36)*	26.93 (8.70); 0.72 to 34.75	1.28 (0.19)***	0.10 (0.05)**	0.40 (0.23)*	
		R^2: 40%	R^2: 59%	R^2: 78%	R^2:72%

(*continued*)

Table 2. Continued.

		Domestic life		Interpersonal relationships	
	Total $n = 67$, age at baseline: 9-13 years	Attendance **(Vine-II)**	Difficulty (Life-H)	Attendance **(Vine-II)**	Difficulty (Life-H)
Environmental characteristics	*n* (%)	Selected predictors of cluster, β (SE); R^2		Selected predictors of cluster, β (SE); R^2	
Housing type (non-adjusted/adjusted home)	38/29 (57/43)	−15.25 (3.1)***	−2.22 (0.44)***	−10.82 (3.34)***	−0.90 (0.48)**
Educational type child (regular/special education)	31/36 (46/54)	−16.57 (3.12)***	−2.08 (0.44)***	−9.52 (3.28)***	−1.27 (0.48)**
Parental education (low/high)	34/23 (51/34) *missing: 10 (15)*				
Marital status parents (single/living with partner)	6/61 (9/91)				
Siblings (0 and 1/2 or more)	12/55 (18/82)				
Life Stressors and Resources: mean (SD); min-max					
– Relational stress/support *(7 items, range 1-4)*	1.7 (0.4); 1 to 2.6			−7.78 (3.99)*	
– Situational stress/support *(13 items, range 1-4)*	1.7 (0.4); 1 to 2.8			6.47 (3.53)*	
		R^2: 60%	R^2: 58%	R^2: 41%	R^2: 24%
Personal characteristics	*n* (%)	Selected predictors of cluster, β (SE); R^2		Selected predictors of cluster, β (SE); R^2	
Gender (Male/female)	45/22 (67/33)				no significant factors
Ethnicity (Dutch/ other)	62/5 (93/7)				
Behavior problems (CBCL): mean (SD); min-max					
– Internalizing behavior problem *(32 items, range 0-64)*	9.4 (7.5); 0 to 34.0				
– Externalizing behavior problem *(33 items, range 0-66)*	8.3 (6.8); 0 to 40.0 *missing: 1*	−0.70 (0.28)**			
Self-competence (SPPC): mean (SD); min-max					
– scholastic competence *(6 items, range 1-4)*	2.9 (0.7); 1.1 to 4.0				
– social acceptance *(6 items, range 1-4)*	3.0 (0.7); 1.3 to 4.0				
– athletic competence *(6 items, range 1-4)*	2.6 (0.6); 1.1 to 3.6		−0.86 (0.39)**		
– physical appearance *(6 items, range 1-4)*	3.2 (0.7); 1.3 to 4.0	6.79 (4.03)*			
– global self-worth *(6 items, range 1-4)*	3.3 (0.6); 1.4 to 4.0	−10.42 (4.15)**		−1.39 (0.78)*	
– motor competence *(6 items, range 1-4)*	2.8 (0.6); 1.8 to 4.0 *missing: 19*	6.21 (2.40)** R^2: 27%	1.17 (0.39)** R^2:18%	1.64 (0.79)** R^2: 12%	

*p-value <0.1.
**p-value <0.05.
***p-value <0.01.
Vine-II: Vineland Adaptive Behavior Scale second edition survey version; Life-H: Assessment of Life Habits 3.1; β: Regression coefficient; SE: standard error; R^2: explained variance; CP: cerebral palsy; GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System; SD: standard deviation; ID: intellectual disability; CBCL: Child Behavior Checklist; GMFM: Gross Motor Function Measure; SPPC: Harter's Social Perception Profile for children; VABS: Vineland Adaptive Behavior Scale.

Table 3. Final prediction models.

	Domestic life						Interpersonal relationships					
	Attendance (Vine-II)			Difficulty (Life-H)			Attendance (Vine-II)			Difficulty (Life-H)		
Prediction models	β (SE)	St β	*p*-value	β (SE)	St β	*p*-value	β (SE)	St β	*p*-value	β (SE)	St β	*p*-value
MACS III-V compared to I-II	−8.49 (2.59)	−0.22	0.002	–	–	–	−12.94 (2.45)	−0.40	<0.001	–	–	–
ID	−10.54 (2.23)	−0.28	<0.001	−1.86 (0.38)	−0.36	<0.001	−13.07 (2.52)	−0.41	<0.001	−1.02 (0.41)	−0.24	0.016
Epilepsy	–	–	–	–	–	–	−17.29 (3.73)	−0.33	<0.001	−3.07 (0.54)	−0.45	<0.001
GMFM	0.35 (0.05)	0.56	<0.001	0.05 (0.01)	0.62	<0.001	–	–	–	0.03 (0.01)	0.37	<0.001
R^2	86.5%			78.9%			73.5%			66.6%		
Extended models	β (SE)	St β	*p*-value	β (SE)	St β	*p*-value	β (SE)	St β	*p*-value	β (SE)	St β	*p*-value
MACS III-V compared to I-II	−8.49 (2.59)	−0.22	0.002	–	–	–	−5.86 (1.60)	−0.18	0.001	–	–	–
ID	−10.54 (2.23)	−0.28	<0.001	−1.44 (0.33)	−0.27	<0.001	−5.45 (1.66)	−0.17	0.002	−0.47 (0.34)	−0.11	0.180
Epilepsy	–	–	–	–	–	–	−4.34 (2.53)	−0.08	0.091	−1.58 (0.50)	−0.23	0.002
GMFM -66	0.35 (0.05)	0.56	<0.001	0.03 (0.01)	0.35	<0.001	–	–	–	0.02 (0.01)	0.23	0.005
VABS fine motor skills	–	–	–	0.07 (0.02)	0.32	0.002	–	–	–	–	–	–
VABS receptive communication	–	–	–	0.10 (0.04)	0.17	0.010	–	–	–	–	–	–
VABS expressive communication	–	–	–	–	–	–	0.72 (0.07)	0.68	<0.001	–	–	–
VABS interpersonal relationships	–	–	–	–	–	–	–	–	–	0.13 (0.02)	0.61	<0.001
R^2	86.5%			86.3%			90.0%			78.5%		

Vine-II: Vineland Adaptive Behavior Scale second edition survey version; Life-H: Assessment of Life Habits 3.1; β: regression coefficient; St β: standardized regression coefficient; SE: standard error; R^2: explained variance; MACS: Manual Ability Classification System; ID: intellectual disability; GMFM-66: Gross Motor Function Measure; VABS: Vineland Adaptive Behavior Scale.

Risk factors

The finding that CP-related factors and body functions predict future participation is in accordance with Dang et al. who found that, over a 5-year period, impairment (including level of gross motor function, level of manual ability, ID, epilepsy, and communication impairments) predicted participation in the domestic life of adolescents with CP [11]. Similarly, we previously found that ID and epilepsy were longitudinally associated with the development of social participation in all PERRIN cohorts, covering a broad age range [26]. The CP-related factors and body functions that we identified as predictors for future participation indicate that more severely affected individuals are at risk of reaching lower levels of participation as young adults. Low motor capacity, low manual ability, ID, and epilepsy are often interrelated in CP, i.e., Individuals with less favourable motor function more often have ID and epilepsy [27]. Nevertheless, a diversity of combinations of these factors occurs in CP, and since we found them as independent predictors of future participation, they should also be considered separately [28]. Those with poorer gross and fine motor function abilities in childhood are likely to continue to experience more motor limitations in adulthood [29], which is associated to lower levels of participation. In addition, their development of new participation skills, for example, in domestic life, may be more challenging, since we know from another study that those with lower gross motor function had more difficulty and needed assistance in participation as they develop into adult roles [6]. Finally, individuals with ID are known to show less favourable development of participation, with development stabilising at relatively low levels during childhood [30]. Therefore, screening children with CP for low motor capacity, low manual ability, ID, and epilepsy may help the timely identification of those at risk for lower participation in future domestic life and/or interpersonal relationships. This group may benefit from early support or treatment in a personalised rehabilitation programme to develop daily activities and participation in domestic life and interpersonal relationships.

Environmental & personal factors

In contrast with earlier work among adolescents with CP [11], this study identified no environmental or personal factors as predictors of participation on the long term. This was in particular unexpected for personal factors, since Dang et al. found that psychological problems were predictors of future participation and we assessed behavioural problems in a similar way to their study [11,31]. It is possible that behaviour problems are predictive over a shorter period of time (e.g., 5 years), but do not predict participation on the long term, because they are subject to change over longer time periods. This might be explained by an earlier study (using the present cohort) that showed that behaviour problems were observed in childhood but diminished during adolescence [32]. This positive development of personal factors with age might explain why childhood behaviour problems do not affect adult functioning. Furthermore, this study found that childhood environmental factors did not predict future participation, while previous studies in childhood showed a strong cross-sectional association between environmental factors (i.e., physical home environment, attitudes of classmates, and social support) and participation [10,11]. A possible explanation for this might be that, in this study, environmental factors were examined in less detail compared to the study of Colver et al. In this study, the childhood environmental factors were found to be predictors in the separate ICF component analyses but did not reach significance in the final models (in which factors of all ICF components were combined). This can be understood when considering that, in accordance with adult roles, the environment of young adults with CP may have changed drastically compared to childhood. Thus, although the environment and the person were previously associated with the current level, or were predictive of the short-term future participation of children, our results show that they do not seem to predict long-term participation in addition to motor capacity, manual ability, ID, and epilepsy, within a sample of individuals with CP with a broad variety of severity levels (reflective of the population of individuals with CP). To confirm this hypothesis, future studies need to examine more environmental factors and study these in more detail (e.g., attitudes of social environment and received treatment) in order to determine whether these are predictive of young adult participation. We additionally advise to consider more homogenous subgroups of CP (e.g., exclusively individuals without ID), since the large variance explained by CP-related factors may overrule that of personal and environmental factors.

Effects of childhood activity and participation level

For difficulty in domestic life, childhood fine motor skills, and communication skills improved the model slightly. For interpersonal relationships, childhood levels of either expressive communication or interpersonal relationships improved both models substantially, indicating that better social skills in childhood are important for young adult participation. It can be understood that communication and interpersonal relationships are related from the importance of communication skills in interacting with others [33], and the association of communication skills with relationships formed at school [34]. Professionals should be alert to appropriate functioning in these domains, particularly for children with low motor capacity, low manual ability, ID, or epilepsy, who are at risk of lower levels of adult participation in interpersonal relationships.

Similarities and differences between participation domains

In this study, similar factors were identified as predictors of future participation for the two studied aspects of participation: attendance and difficulty. Differences were observed between the predictors of participation in domestic life and interpersonal relationships. First, in addition to motor capacity, manual ability, and ID that predicted both domestic life and interpersonal relationships, epilepsy only predicted participation in interpersonal relationships. This factor had a strong predictive value, albeit our sample included few individuals with epilepsy compared to the proportion observed in other CP populations [35]. Associations between epilepsy and interpersonal relationships were also found in a previous study based on the current cohort, as well as in other studies [36–38]. Individuals with epilepsy may experience participation problems in more complex environments, in contrast with the familiar home environment, which is where participation in interpersonal relationships takes place. These problems might be due to increased reticence about going out because of possible seizures, or to practical restrictions, e.g., related to traveling alone. Clinicians could pay special attention to youth with epilepsy regarding experienced obstacles in their participation in interpersonal relationships and take these into account in their rehabilitation treatment. Second, we found that factors regarding motor functioning (e.g., gross motor capacity, manual ability, and fine motor skills) predicted participation in domestic life for a

larger part than interpersonal relationships, which is in line with Dang et al. [11]. This may also be understood from the different constructs of participation in domestic life and interpersonal relationships. Participation in domestic life includes mobility in the home environment and household tasks which presumably have a larger physical component. In conclusion, risk factors and possible modifiable factors differ between the participation domains of domestic life and interpersonal relationships, which suggest the need for individualised goal setting and rehabilitation care to optimise young adult participation.

Strengths and limitations

A strength of this study is the long follow-up (13 years), which allowed to determine early predictors of participation on the long term. Also, despite this long time interval, 63% of the baseline sample was included in the present follow-up. Nevertheless, in view of the relatively small sample size and the large number of childhood factors, we chose to use a forward-stepwise analysis. This approach provided additional insight into the strength of the associations of factors in the different ICF components with the outcomes. The present results and interpretations focused on the strongest childhood activity and participation factors only, although several subdomains were strongly associated with the outcomes. The results categorised by ICF domain of the activity and participation component can provide additional insight into these other associations (Table 2). Finally, it should be noted that our analyses cannot ascertain causal relationships, and intervention studies are needed to determine whether rehabilitation treatment aimed at improving motor capacity, activity and participation in childhood indeed results in improved participation as a young adult.

Conclusions

In this study, childhood factors and activities accounted for 78–90% of the variation in young adult participation in domestic life and interpersonal relationships. For the most part, this was explained by CP-related factors and body functions, whereas environmental and personal factors in childhood did not predict future participation as young adults. Children with CP with limited motor capacity, manual ability, ID, or epilepsy are at risk for future participation restrictions in domestic life or interpersonal relationships in young adulthood. Addressing fine motor skills, communication skills, and social skills in paediatric rehabilitation may contribute to improving participation later in life.

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Disclosure statement

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