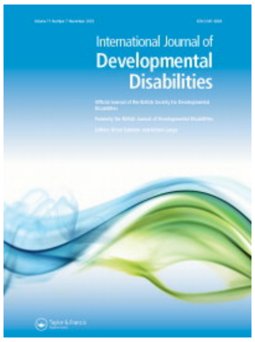

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Participation of children and young people with cerebral palsy in life contexts

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ABSTRACT

Understanding how children and young people with disabilities perceive their participation is essential for promoting inclusive and person-centred practices. This study investigates how children and youth with Cerebral Palsy (CP) perceive their participation and compares these perspectives with those of their caregivers, using *Picture My Participation* to analyse attendance and involvement across diverse life contexts. It also examines key activities and identifies perceived facilitators and barriers to participation. Participants included 40 children and young people with CP (5–20 years) and 40 caregivers, all from the Porto Cerebral Palsy Association, Portugal. Results show notable differences in the perceptions of children and their caregivers regarding attendance and involvement. Children and young people most frequently highlighted Celebrations, Playing with Others, and Family Time, while caregivers prioritised Family Time and School. Facilitators included family support, accessibility, and positive attitudes from peers and community members. Barriers were related to Individual Characteristics and Attitudes, which included negative social interactions and perceived exclusion. Caregivers prioritised Individual Characteristics, giving less weight to Attitudes and more to Environmental Context. The study highlights the need to empower children and youth with CP and foster their inclusion by valuing their perspectives.

Abbreviations: CP: Cerebral Palsy; PCPA: Porto Cerebral Palsy Association; WHO: World Health Organization; ICF-CY: International Classification of Functioning, Disability, and Health for Children and Youth; PmP: Picture My Participation; UN: United Nations

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Participation; children and young people; cerebral palsy; picture my participation; facilitators/barriers

Introduction

Participation, as defined by the World Health Organization (WHO 2001), refers to involvement in real-life situations that stem from the interaction between individuals and their physical and social environments. It encompasses shared decision-making and interaction, enabling individuals to assume various roles and experience diverse situations (Almqvist 2006; Eriksson, Welander, and Granlund 2007). Recognised as a fundamental human right, participation fosters integration and ensures equal opportunities for all children (United Nations 1989). It enhances social competence, responsibility, and political self-determination (Correia et al. 2019), enabling skill development and inclusion in school, home, and community settings (Liao et al. 2019).

Coster and Khetani (2008) expanded on the United Nations' definition, emphasising spatial and temporal dimensions of participation within daily routines. Examining children's participation in significant social contexts, such as family life, offers a holistic understanding of their environment and learning opportunities. Participation is categorised into two dimensions: attendance and involvement. Attendance is an objective measure based on the frequency and diversity of activities (Choi et al. 2022), assessed through instruments, such as time logs and self-reports (Imms and Green 2020). Involvement is a qualitative dimension of participation that can be measured through observation of enjoyment, social interaction, and attention levels (Choi et al. 2022; Coster et al. 2012; Imms et al. 2017). It fosters skill acquisition, self-care, and community involvement, strengthening positive identity and competence (Amaral et al. 2014).

The International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY) (WHO 2007) highlights environmental influences on participation. Cultural, economic, institutional, physical, social, and attitudinal factors can either facilitate or hinder participation, as many environments remain inadequately designed for individuals with disabilities. Consequently, rehabilitation aims to

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maximise participation, recognising environmental factors as crucial for fostering inclusive experiences. However, these same factors may act as barriers, limiting opportunities for children with disabilities (Coster et al. 2012; Imms et al. 2017).

The Unified Theory of Child Development views development as a dynamic interplay between biological, psychological, and social factors (Sameroff 2010). While genetics shapes potential, environmental influences determine its realisation (Sameroff and MacKenzie 2003). Despite efforts toward inclusion, barriers, such as infrastructure limitations and social stigma persist (WHO 2007). Children with disabilities participate less frequently and are less engaged in daily activities than their typically developing peers (Guichard and Grande 2018; Imms et al. 2017). Their parents report more environmental barriers and less support across various settings (Anaby et al. 2014; Bedell et al. 2013; Law et al. 2013; Lim et al. 2016). As disability results from the interaction between individual traits and environmental factors (WHO 2001), non-inclusive settings restrict participation opportunities (Lygnegård et al. 2013). Conversely, supportive environments enhance involvement and foster inclusion (Andersson and Berger 2016), making the promotion of meaningful participation essential for addressing developmental challenges and realising children's potential (Imms et al. 2017).

Cerebral palsy (CP) is a non-progressive disorder caused by early brain injury, affecting motor skills, posture, and muscle tone (Pato et al. 2002). As the most common childhood physical disability in Europe, with a prevalence of 1.77 per 1000 children, CP is frequently accompanied by comorbidities that can further limit participation (Sellier et al. 2016). Including the perspectives of children with CP rather than relying solely on caregiver reports is essential for accurately assessing their experiences (Christensen and James 2008; Tisdall and Punch 2012).

Comprehensive assessment of children's environments – school, home, and community – is essential to identifying barriers and designing inclusive strategies (Amaral et al. 2014). Despite existing legal frameworks, a gap remains in their implementation, highlighting the need for reliable participation assessment tools (Guichard and Grande 2018). The Picture My Participation (PmP) tool, grounded in the ICF-CY framework, enables children with disabilities to self-report their participation and has demonstrated cross-cultural validity, though further research is needed for clinical application (Arvidsson et al. 2020, 2021; Imms et al. 2014; Liao et al. 2019; Shi et al. 2021, 2024).

Environmental barriers, such as limited transportation and social stigma, continue to restrict participation in different contexts, as evidenced by studies in Uganda, Ethiopia, and China (Andrews et al. 2023; Berhanu et al. 2020). Ensuring accessibility and community inclusion is essential for meaningful involvement. Aligning with international frameworks, such as the UN Convention on the Rights of the Child (United Nations 1989), research must centre children's voices and perspectives rather than relying solely on caregivers (Dahan-Oliel, Shikako-Thomas, and Majnemer 2012; Longo et al. 2017).

Recognising children with CP as active agents in their own lives is essential for developing inclusive interventions and policies. This study explores participation across different life contexts by incorporating children's and caregivers' perspectives. The main goals of this study are to describe and compare the perspectives of children and young people with CP and their caregivers regarding the frequency of attendance and level of involvement in various activities, and to identify which activities this population considers most important. Additionally, it seeks to understand the facilitators and barriers to participation in their contexts.

By addressing these goals, this research aims to inform effective interventions that enhance inclusive participation for children and young people with CP, thereby improving their quality of life and integration into society.

Method

Participants

The study included 40 children and young people with CP, aged 5–21 years ($M = 13.15$, SD = 5.16; 50% female), the majority of whom were diagnosed at a young age (77.5%). Additionally, 40 caregivers aged 31–62 years ($M = 45.28$, SD = 6.45) participated, all affiliated with the Porto Cerebral Palsy Association (PCPA). Among these primary caregivers, 77.5% ($n = 31$) were mothers, 15% ($n = 6$) were fathers, and the remainder were stepfathers (2.5%), grandmothers (2.5%), and uncles (2.5%). Thirty-seven percent of the caregivers had completed up to the 9th grade or lower. Inclusion criteria for children and young people were: being between 5 and 21 years of age (the eligible range for the PmP instrument), having a diagnosis of CP, and possessing basic communication and interaction skills sufficient to understand the instrument's content, make choices among four options, and express their thoughts either verbally, through Portuguese Sign Language, or using the

Braille system. Children and young people with uncorrected visual or hearing impairments were excluded. For caregivers, inclusion criteria were having communications skills and being a family related, and the main caregiver (Table 1).

Measures

PmP (Imms et al. 2014) is a participatory research tool designed to capture the experiences and perspectives of children and young people with disabilities, aged 5–21 years, regarding their participation in various life contexts (Imms et al. 2017). This range corresponds to the developmental period during which children can meaningfully engage with picture-supported questions and for whom participation in everyday life remains highly relevant. PmP allows for a deeper understanding of children's experiences and needs, contributing to the identification of areas requiring intervention to promote more inclusive and meaningful participation, by capturing children's and caregivers' perceptions about the child's participation in three main domains: home, school, and community (Liao et al. 2019; Shi et al. 2021). The measure has been translated and adapted for use in multiple countries (e.g. Arvidsson et al. 2021; Balton et al. 2022; Grande, Vilar, and Coelho 2025; Li et al. 2023; Shi et al. 2021). To ensure cultural relevance, research highlights the need to modify specific images (Shi et al. 2021). Studies further confirm that the measure demonstrates strong content validity, internal consistency, and test-retest reliability for children with and without disabilities (e.g. Arvidsson et al. 2020, 2021; Balton et al. 2022; Shi et al. 2021).

Table 1. Sociodemographic characteristics of children and young people and their caregivers.

Variables	*n* (%)
Gender	
Feminine	20 (50.0)
Male	20 (50.0)
Age (mean and standard deviation)	*M* = 13.15; DP = 5.16
Diagnosis since when	
Birth period	31 (77.5)
6 Months	1 (2.5)
8 Months	1 (2.5)
18 Months	1 (2.5)
2 Years	4 (10.0)
5 Years	2 (5.0)
Relationship with children	
Grandmother	1 (2.5)
Mother	31 (77.5)
Stepfather	1 (2.5)
Father	6 (15.0)
Uncle	1 (2.5)
Employment status	
Unemployed	6 (15.0)
Part-time employee	3 (7.5)
Full-time employee	29 (72.5)
Pre-retirement	1 (2.5)
Retired due to disability	1 (2.5)
Caregiver's qualifications	
9th grade or below	15 (37.5)
12th grade	14 (35.0)
Bachelor's degree	10 (25.0)
PhD	1 (2.5)
Social security benefit	
No	27 (67.5)
Yes	13 (32.5)
Monthly Family Income	
>600 €	6 (15.0)
≥600 € a 1200 €	10 (25.0)
≥1200 € a 1800 €	12 (30.0)
≥1800 € a 2500 €	7 (17.5)
≥2500 €	5 (12.5)
Comorbidities/other pathologies	
No	19 (47.5)
Yes	21 (52.5)
Learning Difficulties	
No	15 (37.5)
Yes	25 (62.5)

In a previous study, the PmP child and caregiver versions were translated from English to European Portuguese using the 'forward-only translation with testing' method (Maneesriwongul and Dixon 2004). The authors of the original version were contacted and granted authorisation for the process, providing the original pictures and items (for more detail, cf. Grande, Vilar, and Coelho 2025).

The PmP includes two versions: one for children and young people and another for their primary caregivers.

The version for children and young people is a semi-structured interview supported by images to elicit their voice and perspective on participation (Bailey et al. 2015). The use of the Talking Mats approach, in which items and response options were converted into images, facilitates the conversation with the child (Liao et al. 2019). The child version includes a prioritisation section and 20 daily activities. Children were asked to assess their frequency of attendance for each activity using a 4-point scale and their perceived level of involvement on a 3-point scale (1 = Very Involved; 2 = Somewhat Involved; 3 = Minimally Involved). The caregiver version of the PmP includes measures such as sociodemographic information and the Ten-Question Questionnaire, which assesses neurological impairments in children and young people (Mung'ala-Odera et al. 2004). This questionnaire comprises 10 binary response items to assess cognitive, sensory, and motor impairments and epilepsy (Arvidsson et al. 2021; Durkin 1995). Finally, a list can also be found of 20 daily activities regarding children's frequency of attendance, rated in a 4-point scale (1 = Always; 2 = Sometimes; 3 = Not really; 4 = Never, and children's involvement while attending each daily activity. Involvement is rated on a 3-point scale (1 = Very Involved; 2 = Somewhat Involved; 3 = Minimally Involved). Additionally, the PmP interview asks caregivers to prioritise their child's three most important activities. In the final section, caregivers were asked to identify the key barriers and facilitators for the priority activities, which were coded according to five categories of facilitators/barriers: products and technology, natural environment and human changes to the environment, support and relationships, attitudes and services, and systems and politics.

Each child and young person–caregiver pair received tailored materials, including the sociodemographic questionnaire and PmP versions. Caregivers completed their forms individually in the presence of the researcher, with clarifications provided as needed, while children and young people were supported in a context that minimised caregiver influence. To prevent data contamination, both completed their instruments independently. The procedures ensured systematic, ethically grounded data collection under rigorously controlled conditions.

Procedures

Data collection. The study was conducted in two phases. The first phase was a pilot study, marking the first application of the PmP in the Portuguese context with children and young people with CP. It involved eight families with participants aged 5–21 years and their caregivers, recruited through the PCPA. This stage allowed refinement of the instruments, particularly the Sociodemographic Data Questionnaire, based on participant feedback to improve the quality of the main study. During this stage, the study was introduced and disseminated through PCPA, and interested families contacted the researcher to arrange data collection.

The second phase followed the same procedures with a larger sample and took place between May and December 2023. Data collection was conducted in single one-hour sessions: children and young people completed interviews lasting 20–30 min, depending on the level of assistance needed, while caregivers completed theirs in 15–20 min. The level of assistance needed referred to the degree of support required by participants to complete the PmP interview, which could include simplified language, repetition of questions, support with pointing to pictures, or the use of alternative and augmentative communication (AAC) strategies when applicable. Writing support was not necessary, as responses were written directly by the researcher. Ethical principles were rigorously upheld, with voluntary participation, confidentiality, informed consent/assent, and adapted communication methods (simplified language, oral reading, and Portuguese Sign Language).

Data analysis

Quantitative data were processed using IBM SPSS Statistics, version 29.0 (IBM Corp., Armonk, NY). Descriptive and inferential analyses were conducted, including non-parametric methods for non-normal data distributions. The Wilcoxon test was used to compare the frequency scores of each activity at the item level between the two groups. The ranking of the 20 items was determined by the frequency with which each item was selected as most important by both groups. Spearman's rank correlation coefficients were used to examine relationships. The results were interpreted based on the magnitude of differences between groups, calculated by converting the Z values into r values using the formula suggested by Rosenthal (1991) and recommended by Field (2009).

Thematic content analysis was applied to the qualitative data following the approach of Elo and Kyngäs (2008), as this method is particularly suitable for systematically identifying and categorising patterns within participants' narratives. In this study, it was used to examine perceptions of barriers and facilitators as reported by both groups. Coding and analysis were conducted collaboratively to ensure consistency and depth in understanding participants' perspectives (Appendix 1). Two independent researchers coded 20% of the caregivers' responses, achieving a high level of agreement (90%). Discrepancies in coding were resolved through discussion, and responses related to participation barriers, facilitators, and activity prioritisation were subsequently quantified.

Ethical considerations

The study received ethical approval from the University Ethics Committee (Ref. No. 2023/04-02b).

Before data collection, informed consent was obtained from adults and assent from children and young people, adhering to the American Psychological Association ethical standards and the General Data Protection Regulation. Participation was voluntary, and children and young people were informed of their rights and the purpose of the study.

Results

Sociodemographic characteristics

According to the Ten Questions Questionnaire, 65% of caregivers reported significant motor delays in children and young people, with 72.5% experiencing difficulties in walking, arm movement, or limb stiffness. Despite this, 95% could understand caregivers' requests, 75% learned similarly to peers, and 92.5% communicated verbally with recognisable words. Regarding support, all participants received psychological services, while 27.5% accessed psychiatry, and 22.5% received physiotherapy and occupational therapy. Additionally, 47.5% received external support, mainly physiotherapy (22.5%) and combined therapy (7.5%). Services were provided weekly in 40% of cases. These data reflect caregiver perceptions only, as collected through the PmP instrument, which does not involve clinical assessment or diagnostic confirmation.

Description and comparison of frequency scores

Table 2 presents data on PmP frequency, including Item-by-item comparison of the frequency of attendance scores between children and young people and their primary caregivers. Statistically significant differences, ranging from moderate to large, were observed in activities, such as Family Meals, Meal Preparation, Family Time, Caring for the Family, Caring for Animals, and Shopping.

These results suggest that children and young people perceived themselves as participating more frequently in Family Meals, Meal Preparation, and Family Time. In contrast, caregivers reported that, in their perception, children and young people were more involved in activities, such as Caring for the Family, Caring for Animals, and Shopping.

Description and comparison of involvement scores

Table 3 presents data on PmP involvement, highlighting statistically significant differences in involvement scores between children and young people and their primary caregivers in activities such as Caring for the Family, Organised Leisure Time, Shopping, and Meal Preparation, with effect sizes ranging from moderate to large.

These results indicate that children and young people perceived themselves as more engaged in activities such as Caring for the Family, Organised Leisure Time, and Shopping. In contrast, caregivers reported that, in their involvement, children and young people were more engaged in Meal Preparation.

To conclude, the results presented in Tables 2 and 3 highlight the activities in which children and young people most often took part, as well as those in which they showed the greatest level of involvement. According to the children and young people themselves, the activities with the highest frequency of participation included School, Family Meals, Organised Leisure Time, Health Center visits, and Celebrations. In contrast, they reported feeling most engaged in Organised Leisure Time, Celebrations, Trips and Visits, and Playing with Others.

Caregivers, however, perceived that children and young people participated more frequently in Family Meals, Family Time, School, Personal Care, and Health Centre visits. Nevertheless, they believed that the strongest involvement occurred in Family Meals, Celebrations, Family Time, and Playing with Others.

Table 2. Item-by-item comparison of the frequency of attendance scores between young people and their primary caregivers.

Picture my participation activity item	Children ($n = 40$)			Main caregivers ($n = 40$)					
	Min–Max	*M*	*SD*	Min–Max	*M*	*SD*	*p* Value	*Z*	*r*
Personal care	1–4	3.25	1.01	1–4	3.45	0.75	0.124	1.54	0.24
Family mealtimes	2–4	3.68	0.53	3–4	3.88	0.33	0.024*	2.31	0.37
My own health	1–4	2.55	1.15	1–4	2.30	1.16	0.143	−1.46	−0.23
Gathering supplies	1–4	2.80	1.18	1–4	2.83	0.84	0.675	0.42	0.07
Meal preparation	1–4	1.45	0.71	1–4	2.10	0.84	<0.001*	3.87	0.61
Cleaning at home	1–4	2.53	1.01	1–4	2.35	0.83	0.196	−1.29	−0.20
Caring for family	1–4	3.10	0.93	1–4	1.85	0.98	<0.001*	−3.86	−0.61
Caring for animals/pets	1–4	2.80	1.20	1–4	2.45	1.08	0.028*	−2.20	−0.35
Family time	1–4	3.35	0.66	2–4	3.68	0.57	0.009*	2.60	0.41
Celebrations	1–4	3.53	0.72	2–4	3.63	0.63	0.552	0.60	0.09
Playing with others	1–4	3.45	0.68	2–4	3.20	0.72	0.103	−1.63	−0.23
Organised leisure	2–4	3.55	0.64	1–4	3.32	0.86	0.088	−1.71	−0.27
Quiet leisure	1–4	2.98	0.89	1–4	2.90	0.90	0.599	−0.53	−0.08
Spiritual activities	1–4	1.83	1.01	1–4	1.95	0.96	0.282	1.08	0.17
Shopping	1–4	3.30	0.76	1–4	2.78	1.03	0.002*	−3.09	−0.49
Social activities	1–4	2.70	1.02	1–4	2.88	0.99	0.360	0.92	0.14
Health centre	1–4	3.53	0.72	2–4	3.40	0.67	0.414	−0.82	−0.13
School	1–4	3.83	0.55	2–4	3.65	0.66	0.171	−1.37	−0.22
Overnight visits and trips	1–4	3.10	0.93	1–4	2.90	0.96	0.227	−1.21	−0.19
Paid/unpaid employment	1–4	1.38	0.74	1–4	1.15	0.53	0.059	−1.89	−0.30

$p < 0.05$*.

Table 3. Item-by-item comparison of involvement scores between children and young people and their primary caregivers.

Picture my participation activity item	Children ($n = 40$)			Main caregivers ($n = 40$)					
	Min–Max	*M*	*SD*	Min–Max	*M*	*SD*	*p* Value	*Z*	*r*
Personal care	1–3	2.25	0.81	1–3	2.33	0.73	0.439	0.78	0.12
Family mealtimes	1–3	2.58	0.64	1–3	2.75	0.54	0.115	1.58	0.25
My own health	1–3	2.10	0.87	1–3	1.83	0.84	0.074	−1.79	−0.28
Gathering supplies	1–3	1.85	0.77	1–3	2.05	0.68	0.187	1.32	0.21
Meal preparation	1–3	1.33	0.66	1–3	1.78	0.83	0.005*	2.80	0.44
Cleaning at home	1–3	1.68	0.73	1–3	1.60	0.74	0.572	−0.57	−0.09
Caring for family	1–3	2.45	0.75	1–3	1.68	0.89	0.001*	−3.24	−0.51
Caring for animals/pets	1–3	2.15	0.95	1–3	1.93	0.86	0.115	−1.58	−0.25
Family time	1–3	2.50	0.60	2–3	2.68	0.47	0.162	1.40	0.22
Celebrations	1–3	2.65	0.53	1–3	2.70	0.56	0.686	0.40	0.06
Playing with others	1–3	2.60	0.63	1–3	2.53	0.64	0.572	−0.57	−0.09
Organised leisure	2–3	2.73	0.45	1–3	2.45	0.71	0.026*	−2.22	−0.35
Quiet leisure	1–3	2.40	0.84	1–3	2.28	0.78	0.337	−0.96	−0.15
Spiritual activities	1–3	1.60	0.81	1–3	1.43	0.64	0.151	−1.44	−0.23
Shopping	1–3	2.43	0.68	1–3	2.08	0.80	0.012*	−2.52	−0.40
Social activities	1–3	2.00	0.82	1–3	2.08	0.80	0.614	0.50	0.08
Health centre	1–3	2.20	0.76	1–3	2.30	0.69	0.488	0.69	0.11
School	1–3	2.33	0.69	1–3	2.43	0.68	0.414	0.82	0.13
Overnight visits and trips	1–3	2.63	0.63	1–3	2.38	0.81	0.072	−1.80	−0.28
Paid/unpaid employment	1–3	1.28	0.64	1–3	1.10	0.38	0.149	−1.44	−0.23

$p < 0.05$*.

Comparison of activity ranking based on the frequency of selected important items

Table 4 presents item-by-item frequency data on the 20 PmP activities selected as important for attendance. Both groups chose Organised Leisure Time most frequently (17.5%). For children and young people, the most cited activities were Celebrations (13.3%), Playing with Others (9.2%), and Family Time (9.2%). Caregivers, however, emphasised Organised Leisure Time (17.5%), Family Time (11.7%), and School (10.8%).

A Spearman correlation analysis revealed a strong association ($r = 0.61$) between the top three ranked activities for children and young people and caregivers, indicating significant agreement regarding important activities for attendance and suggesting a shared understanding between the two groups.

Comparison of barriers and facilitators between children and young people and their caregivers

The results indicate that children and young people and their caregivers shared similar views on perceived barriers and facilitators to participation in daily life. Table 5 presents the most frequently occurring codes assigned to their responses, along with representative examples.

Children and young people with CP primarily identified Individual Characteristics as barriers (45.8%), citing issues, such as mental distraction, self-restraint, and unachieved goals, followed by Attitudes (29.2%), which included negative social interactions and perceived exclusion. Caregivers similarly emphasised Individual Characteristics (65%) but attributed slightly less importance to Attitudes (13.3%) and more to Environmental Context (11.7%), noting physical access challenges and architectural barriers.

Both children and young people and caregivers identified Support/Relationships as the primary facilitator of participation, as noted by 71.7% of children and young people and 55% of caregivers, who emphasised positive social interactions and encouragement. Individual Characteristics were also highlighted as facilitators, with 15% of children and young people and 30.8% of caregivers underscoring traits such as sociability, motivation, and commitment, indicating a greater emphasis on personal attributes by caregivers.

Products/Technology were similarly perceived as facilitators, cited by 5.8% of children and young people (e.g. listening to music and playing video games) and 4.2% of caregivers (e.g. using exercise equipment, mobile phones, and music).

Discussion

Children and young people and caregivers' perspectives about attendance in daily life activities

This study aimed to describe and compare the perspectives of children and young people with CP with their respective caregivers regarding the frequency of attendance and involvement of these children and young people in different activities, as well as identify the most important activities this population considers.

Findings reveal an interesting divergence between the perceptions of children and young people with

Table 4. Ranking order of activities about the frequency of the items selected as most important.

Picture my participation activity item	Children ($n = 40$)	Main caregivers ($n = 40$)
Personal care	5 (4.2)	8 (6.7)
Family mealtimes	6 (5.0)	4 (3.3)
My own health	3 (2.5)	1 (0.8)
Gathering supplies	1 (0.8)	0 (0.0)
Meal preparation	0 (0.0)	1 (0.8)
Cleaning at home	0 (0.0)	4 (3.3)
Caring for family	5 (4.2)	1 (0.8)
Caring for animals/pets	7 (5.8)	1 (0.8)
Family time	11 (9.2)	14 (11.7)
Celebrations	16 (13.3)	8 (6.7)
Playing with others	11 (9.2)	10 (8.3)
Organised leisure	21 (17.5)	21 (17.5)
Quiet leisure	10 (8.3)	7 (5.8)
Spiritual activities	2 (1.7)	2 (1.7)
Shopping	7 (5.8)	3 (2.5)
Social activities	2 (1.7)	11 (9.2)
Health centre	1 (0.8)	4 (3.3)
School	7 (5.8)	13 (10.8)
Overnight visits and trips	4 (3.3)	6 (5.0)
Paid/unpaid employment	1 (0.8)	1 (0.8)
Total	120 (100.0)	120 (100.0)

Note: Data are given in *n* (%) format.

Table 5. Comparison of barriers and facilitators between children and young people and their main caregivers, regarding the three activities selected as priorities.

Code assigned to all priority activities	Child/young facilitator	Child/young barrier	Caregiver facilitator	Caregiver barrier
Support/relationship	86 (71.7)	2 (1.7)	66 (55.0)	0 (0.0)
Product/technology	7 (5.8)	7 (5.8)	5 (4.2)	3 (2.5)
Natural/human environment	5 (4.2)	9 (7.5)	3 (2.5)	14 (11.7)
Attitudes	0 (0.0)	35 (29.2)	0 (0.0)	16 (13.3)
Services/systems/policies	3 (2.5)	5 (4.2)	3 (2.5)	1 (0.8)
Individual features	18 (15.0)	55 (45.8)	37 (30.8)	78 (65)
Nothing	1 (0.8)	7 (5.8)	4 (3.3)	8 (6.7)
Everything	0 (0.0)	0 (0.0)	2 (1.7)	0 (0.0)
Total	120 (100.0)	120 (100.0)	120 (100.0)	120 (100.0)

Note: Data are given in *n* (%) format.

disabilities and their caregivers regarding their frequency of attendance in daily life activities, similar to other studies that indicated a discrepancy in the perceptions of primary caregivers and children and young people regarding perceived participation (Dada et al. 2020; Liao et al. 2019). While children and young people reported lower frequency in Family Time, Meal Preparation, and Family Meals, they indicated a higher frequency of attendance in caregiving, particularly in Caring for the Family, Caring for Animals, and Helping with Shopping, results also reported by Zheng et al. (2023). The level of family support available for each activity at home may also explain this phenomenon. Caregivers' perceptions of environmental support at home influence children's attendance in household tasks (Albrecht and Khetani 2017). In this context, parental protection may be seen as an expression of their responsibility and concern for their children's health issues.

Additionally, data indicated that children and young people reported less attendance in more complex activities, such as meal preparation. These are skills that caregivers can develop with children and young people, thereby promoting successful participation and preparing them for the future. Thus, participation and skill acquisition are influenced by the severity of the children's medical conditions and family expectations (Law et al. 2013). These findings align with previous studies that have shown similar results. Dada et al. (2020) found that children and youth with special needs often have a unique perspective on their participation experiences, which may differ from their caregivers' perceptions. This discrepancy can be attributed to various factors, including the children's and youth's growing autonomy and self-awareness, as well as caregivers' expectations and interpretations regarding their presence in family and household activities (Liao et al. 2019). On the other hand, children and youth reported higher frequency in activities such as caring for the family and pets and helping with grocery shopping, which aligns with the study by Liao et al. (2019), who demonstrated similar results in these areas.

Community participation, including social activities and shopping, often involves physical effort or mobility, which can be challenging. As a result, caregivers expressed concerns about children and youth becoming tired or injured. Nevertheless, there was a convergence between children and youth and caregivers regarding the frequency attributed to school and organised leisure activities. Formal learning in school is considered the most important activity by children and youth, and their participation is linked to their health and well-being (John-Akinola and Nic-Gabhainn 2014). While some studies indicate that children participate less in school due to health conditions (Zheng et al. 2023; Whitney and Peterson 2019), in our research, school remained one of the activities with the highest attendance. Liao et al. (2019) identified school and organised leisure activities as key elements in the lives of children and youth with special needs because they provide significant opportunities for learning, socialisation, emotional support, and the development of social, physical, and cognitive skills, as well as promoting social inclusion and self-esteem.

Children and young people and caregivers' perspective about involvement in daily life activities

Regarding involvement, the results showed that the scores given by children and young people were significantly higher than those of primary caregivers in activities, such as Caring for the Family, Organised Leisure Time, and Shopping, but significantly lower for the item Meal Preparation. This pattern suggested a division of responsibilities and interests, with children and young people taking on more active roles in some areas. Despite the lack of statistical evidence, these activities played a significant role in their lives, providing opportunities for socialisation, enjoyment, and enriching experiences. On the other hand, caregivers perceived greater involvement of children and young people in activities, such as Family Meals, Celebrations, and Family Time. This perception may reflect caregivers' expectations regarding children and young people's involvement in family and domestic activities, as well as their perception of what is most beneficial or prioritised for their well-being and development. These findings align with previous studies, where participation perspectives can vary between children and young people and their caregivers, particularly concerning specific activities and the value attributed to them (Liao et al. 2019; Zheng et al. 2023). Children and young people may value activities that provide autonomy, enjoyment, and social interaction, while caregivers may emphasise activities that promote family support, structured routines, and emotional security (Liao et al. 2019; Zheng et al. 2023).

Activities considered most important by children and young people and their primary caregivers

Regarding the importance attributed to activities, we found that the top three activities valued by primary caregivers largely coincided with the choices of children and youth. This finding is aligned with Zheng et al. (2023) and stems from a proportional synthesis of preferences, revealing that both children and young people and caregivers share similar expectations regarding activities. Both groups considered Organised Leisure Time and Family Time as priority activities, although children and youth also valued Celebrations and Birthdays, while caregivers prioritised formal learning at school.

The study suggested that while children and young people and caregivers share similar expectations regarding meaningful activities, their priorities were not entirely aligned. Children and youth focused on enjoyable, frequent, or achievable activities, such as organised leisure, family celebrations, and social interactions. In contrast, caregivers prioritised activities they perceived as beneficial for development, such as family time, school, play, and structured leisure. This dynamic reflects previous research indicating that while caregivers may represent their children in decision-making, children and young people with CP may have distinct perceptions of their participation (Costa, Brauchle, and Kennedy-Behr 2017; Huus et al. 2015). Based on our findings, we recommend further analysis to explore how the frequency of participation, level of involvement, or interest in specific activities may influence how individuals perceive the importance of those activities. Such an approach could provide valuable insights to support skill development and enhance participation, as also suggested by Zheng et al. (2023).

Key facilitators promoting active participation among children and young people and their caregivers

Family was identified as a key participation facilitator, with positive attitudes, affection, and support encouraging children and youth to engage in activities and reinforcing family bonds (Gilmore, Mann, and Pennell 2022; Steinhardt et al. 2021). Expressions of interest from family members can also inspire others to adopt a similarly supportive stance. Beyond the family, friendships provide a sense of belonging and boost emotional well-being, especially involving individuals with positive attitudes. Additionally, professionals and support figures, including teachers and healthcare providers, played vital roles in fostering participation by offering care, guidance, and inclusive opportunities, highlighting the importance of strong school-family partnerships (Conchar et al. 2016; Du et al. 2016; Frantz et al. 2011; McConkey et al. 2013).

Although almost half of the children and young people with CP identified their individual characteristics as barriers to participation (46%), a smaller group (15%) perceived certain personal traits – such as intrinsic motivation, physical abilities, and self-confidence – as facilitators. For these children, engaging in physical activities was described as promoting health and enhancing self-esteem, particularly when such activities were enjoyable and fulfilling (Huus et al. 2021). Additionally, a willingness to acquire new skills further expanded participation opportunities, reframing individual traits as strengths rather than challenges. Previous research has also highlighted the significant role of products and technology as assistive tools that foster independence, communication, and social inclusion (Conchar et al. 2016; Frantz et al. 2011). Technological adaptations are crucial in promoting participation and inclusion for children and young people with CP across various settings, enhancing autonomy, personal development, and social participation (Columna et al. 2015; Conchar et al. 2016; Glumac et al. 2009; Hui et al. 2018; McConkey et al. 2013; Nelson et al. 2017).

Key barriers hindering active participation according to children and young people and their caregivers

The results revealed that children and young people with CP encountered barriers at multiple levels, restricting or discouraging their participation in everyday life. These barriers reflected an interplay between individual, social, and environmental factors.

Children and youth with CP primarily emphasised individual and social barriers, such as limited physical abilities, fatigue, concentration difficulties, and negative social experiences (e.g. exclusion or bullying). These findings are consistent with previous studies highlighting how internal struggles and stigmatisation can undermine confidence and restrict participation opportunities (Bantjes et al. 2015; Earde et al. 2018; Frantz et al. 2011; Huus et al. 2021; Memari et al. 2015).

From the perspective of children and youth, individual characteristics were the most frequently cited barriers. Difficulties, such as limited physical abilities, fatigue, or challenges with concentration often reduced their participation. Some also reported feelings of self-consciousness or frustration when unable to meet expectations, which is consistent with research showing that children with CP may experience vulnerability and withdrawal in group settings (Frantz et al. 2011; Huus et al. 2021; Memari et al. 2015). These internal struggles could lead to discomfort and reluctance to engage, perpetuating a cycle of avoidance that limits opportunities for skill development and social integration.

Social barriers were also emphasised, particularly negative attitudes from peers, teachers, or community members. Experiences of exclusion, bullying, or stigmatisation diminished children's confidence and willingness to participate, echoing findings from disability studies that highlight the detrimental effects of stigma on self-esteem and participation (Bantjes et al. 2015; Earde et al. 2018).

Similarly, caregivers also highlighted individual characteristics as barriers but placed greater emphasis on environmental factors, such as the limited accessibility of schools, recreational facilities, and community spaces, as well as the lack of adapted equipment or institutional support. This perspective aligns with evidence that physical and organisational environments often fail to provide adequate accommodations for children with disabilities (Bedell et al. 2013; Kang et al. 2017; Law et al. 2013). In sum, while children emphasised personal and social experiences, caregivers drew attention to broader systemic challenges. Addressing participation, therefore, requires multilevel interventions that combine support for children's self-confidence and motivation with improvements in accessibility, professional training, and inclusive attitudes across families, schools, and communities.

Limitations and future research

This study provides valuable insights into the participation of children and young people CP, highlighting their often underrepresented perspectives. It compares the views of children and youth and their caregivers to offer a broader understanding of participation dynamics. However, the study has limitations, including a small sample size, convenience sampling, and the exclusion of participants with severe cognitive and communicative disabilities, which may affect the generalisability of the findings, thus these findings should be interpreted as exploratory. The geographic concentration of participants also limits the applicability of the results. Future research should include a more diverse sample, age-stratified samples, adopt longitudinal designs, and employ a biopsychosocial approach to understand the factors influencing participation.

Conclusion

This study highlights the importance of increasing attention to the perspectives and opinions of children and young people with CP in research and interventions. Their insights, alongside those of caregivers, offer complementary views essential for developing well-rounded, inclusive approaches. Practitioners should tailor interventions to the specific needs of these individuals and actively involve them from the outset. Moreover, promoting the fundamental rights of children and youth with disabilities is vital not only for their health and education but also for the cohesion and prosperity of societies. Shonkoff et al. (2012) emphasised that investing in this population supports sustainable development, underlining the need for inclusive services and policies prioritising child and youth functionality through a holistic and rights-based framework.

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Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Appendix 1. Definition of codes for PmP barriers and facilitators.

Code	Code definition	Example
Products and technology	Related to products, instruments, equipment, or technology adapted or specially designed to promote the functionality of people with disabilities.	I use my cell phone to set reminders to take my medication.
Natural environment and human alterations to the environment	Related to animate and inanimate elements of the physical or natural environment and to components of that environment modified by people.	I cannot use my wheelchair when we go hiking.
Support and relationships	Related to people or animals that provide practical, physical, or emotional support by caring for, protecting, and assisting, as well as relationships with other people in all aspects of daily life, excluding the attitudes of those who provide support.	I like to go shopping alone, and I can go alone with my guide dog.
Attitudes	Related to attitudes observable through the consequences of habits, practices, ideologies, norms, factual and religious beliefs, and to the attitudes of people outside the person with a disability (not the person with a disability themselves).	I love pets, but my mom will not let me have a dog.
Services, systems, and policies	Services related to structured public, private, or voluntary services established at the local, community, regional, national, or international level that meet the needs of persons with disabilities. Systems and policies related to administrative control and control mechanisms and rules, regulations, and standards established at the different levels mentioned above, in various sectors of society.	I would like to go to the neighbourhood school, but the school will not let me take classes there.
Individual Characteristics	Related to unique qualities, traits, or attributes that a person has/attribute. These may include physical, cognitive, emotional, behavioural, and social factors.	I am a motivated person and eager to learn more. My physical abilities do not allow me to do that activity.
All or Nothing	Related to the totality or absence of experiences, activities, interactions, and contexts in which the child/young person participates.	I can do anything. I cannot do anything.