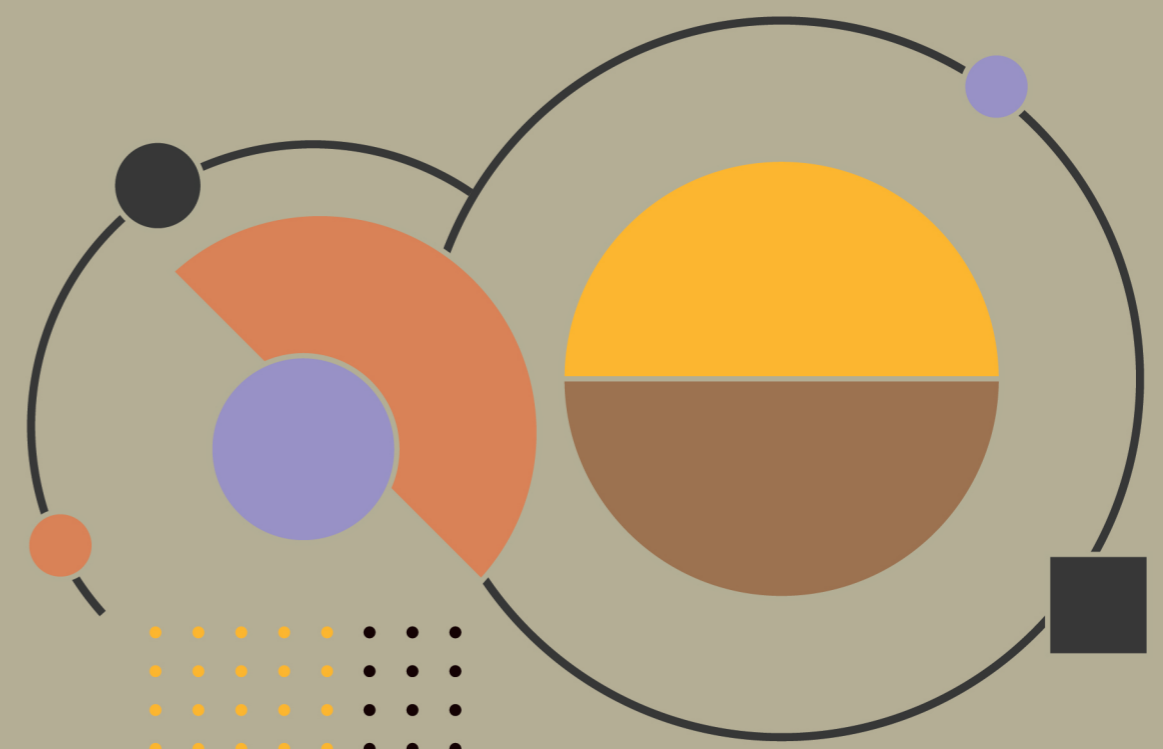


COMMUNITY PARTICIPATION OF CHILDREN WITH CEREBRAL PALSY IN SERBIA : CONCEPTUAL CONSIDERATIONS AND EVALUATION



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CONCEPTUAL CONSIDERATIONS AND EVALUATION



Institute of Criminological and Sociological Research

MILENA MILIĆEVIĆ



Community participation of children with
cerebral palsy in Serbia:
Conceptual considerations and evaluation

Dr Milena Milićević

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*“We can (and are able, truly) to make life better for all...
It just takes more effort,
and a little effort goes a long way.”*

WPC

To Billy Corgan

*Your persistence of staying true to yourself and your hard work are inspiring.
Thank you.*

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Abbreviations

BFMF	Bimanual Fine Motor Function
CAPE	Children’s Assessment of Participation and Enjoyment
CFCS	Communication Function Classification System
CP	cerebral palsy
FPQ	The Frequency of Participation
GMFCS	Gross Motor Function Classification System
GMFCS–E&R	Gross Motor Function Classification System – Expanded and Revised
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health – Children and Youth Version
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
ID	intellectual disability
LIFE-H	Assessment of Life Habits
MACS	Manual Ability Classification System
PEM-CY	Participation and Environment Measure for Children and Youth
SCPE	Surveillance of Cerebral Palsy in Europe
TD	typical development
WHO	World Health Organization

INTRODUCTION

Participation was introduced as a concept in 2001 when the World Health Organization (WHO) published the *International Classification of Functioning, Disability and Health – ICF* (WHO, 2001). Since then, as a significant aspect of overall human functioning, participation has become the subject of the growing interest of the professional and scientific public. Defined as a person's "involvement in life situations", participation is a central part of a child's development, but also the basis of the experienced quality of life at all ages (Imms, 2020; Imms et al., 2008; Kang et al., 2014; King et al., 2003; Mc Manus et al., 2008; Orlin et al., 2010). Besides, it plays a key role in developing children's ability to acquire new skills and to develop meaningful relationships with others, to communicate. Regarding school activities, it is considered essential for learning and relevant in educational and social terms (Law, 2002; Simeonsson et al., 2001). Also, participation provides opportunities to gain life experience, social skills and competencies, to connect with other people and achieve social connections, with a positive impact on life satisfaction, sense of ability, health and mental and emotional well-being (Bart & Rosenberg, 2011; Engel-Yeger et al., 2009; Hammel et al., 2008; Law, 2002; Law et al., 2003).

The nature and extent of participation are defined by the interaction between the person and the dimensions of the environment (Imms, 2020; Simeonsson et al., 2001). The role of participation, including the social one, is notable in a central premise of the shift from a medical to a social model of disability (Simeonsson et al., 2001). Participation can also be influenced by culture, especially in a community environment. This influence is mediated by the social environment and family routines as basic aspects of culture. Thus, differences between cultures are visible through attitudes toward children and expectations when it comes to skills that are developed and behaviours that are encouraged in children (Engel-Yeger et al., 2007).

Cerebral palsy is the most common cause of childhood motor disability (Pakula et al., 2009; Rosenbaum, 2003), accounting for over 60% of severe motor disabilities (Cans, 2003). Cerebral palsy is complex and characterized by wide variations in motor functioning, followed by limitations in sensation, perception, cognition, communication, behaviour and other health conditions, such as epilepsy and secondary musculoskeletal problems (Rosenbaum et al., 2007). As one of the most common etiological factors of motor behaviour disorders, cerebral palsy limits the development of abilities with all the consequences that accompany, limit or disable motor, cognitive, intellectual, emotional and social functioning of these persons, leading to a constant need for intensive and continuous support (Milićević et al., 2011). By comparing the cumulative data of relevant functional domains in subjects with cerebral palsy (Body functions and structures, Activities and participation, Environmental factors, all according to ICF Checklist 2.1a), it was confirmed that numerous physical impairments and disorders interfere with the functioning of these individuals in the environment (Nedović et al., 2012). Although

participation in recreation and community life improves before age 23 years for those in GMFCS levels III and IV, long-term course of overall participation in the mid- and late 20s for individuals with cerebral palsy shows increase of difficulties, particularly in domestic life, education and employment (van Gorp, Van Wely, et al., 2019).

Overall, the environment, attitudes, and barriers are additional factors that limit the functioning, activities, and participation of children with cerebral palsy. Thus, the life of persons with cerebral palsy is accompanied by a high risk for the development of secondary conditions that compromise functional abilities, daily life activities, as well as participation, and negatively affect the quality of life (Svien et al., 2008). Given that this is a heterogeneous group of disorders and that the clinical picture includes a wide range of impairments and comorbidities (Rosenbaum et al., 2007), the question is whether the consequences of this condition can be seen in the involvement of children from this population in different life situations and to what extent participation is reduced.

If individuals are not given the opportunity to participate in a range of different activities, then they are actually denied the opportunity to fulfil their potential as active participants in life at home, in the family, and the community (King et al., 2003). Starting from equality and guaranteed human rights, it is important to understand the relationship, differences, but also the similarities of the participation of children with disabilities or children with typical development, i.e. children from the general population. In addition, determining the characteristics of participation in a particular environment is the first step in developing strategies and planning interventions in the field of special education and rehabilitation. If the focus of special education and rehabilitation of persons with motor disorders or physical disabilities is on improving their overall well-being, then, as a priority, strengthening and improving their involvement in life situations should be set. However, it is necessary to empower them to participate in activities that are meaningful to them and in which their needs and desires are respected, to include them in everyday life with others and to provide a sense of fulfilment.

Participation is paramount for children with cerebral palsy, as a primary goal and an entry point of rehabilitation services and an outcome desired by parents (Arakelyan et al., 2019; Bedell et al., 2011, 2013; Coster & Khetani, 2008; Palisano et al., 2012). Improving and optimizing the participation of children with developmental disabilities and chronic diseases, including cerebral palsy, in different settings is one of the key goals of special education and rehabilitation, as well. Risk factors and possible modifiable factors differ between the participation domains across settings, implying the need for individualised goal setting to optimize participation (van Gorp, E. Roebroek, et al., 2019).

A majority of research on the participation of children with disabilities across different settings has been focused on school-age children from six years and above and conducted in developed countries with adequate resources (Raghavendra, 2013). Therefore, less is known on the participation of children with disabilities in developing countries with fewer resources (Schlebusch et al., 2020). In Serbia, children with intellectual disability and children with autistic spectrum disorders participate in fewer social, leisure and recreational activities compared to their typically developing peers

(Kaljača et al., 2018). Activities in which they participated are described as stereotypical and highly structured. A significantly smaller number of children with intellectual disability and autistic spectrum disorders were able to participate independently in social activities, as well. Another research indicated that a lack of programs and services for children cerebral palsy was perceived as a barrier more frequently and with stronger influence in suburban communities compared to urban and rural ones (Milićević & Nedović, 2017b). Overall, participation is inadequately represented in the planning and evaluation of services in rehabilitation (Dimitrijević, 2014; Milićević & Nedović, 2017a, 2020).

Besides, referring to the fact that participation is determined partly by socio-cultural factors and the value system, we believe that it is justified to explore the characteristics of participation of children with cerebral palsy and the structure of environmental factors in Serbia. Participation in community-based activities is not an exception. New findings may aid the identification of families with a child with cerebral palsy who might require interventions to improve their participation in this setting.

The empirical basis of this research is designed to contribute to a better understanding of participation in different environments, as well as to a better understanding of the problems and challenges that children with cerebral palsy and their families face every day, by describing the specifics of participation characteristics and highlighting important factors. The findings could contribute to a new insight into the specific environmental conditions under which influence the participation of children from this population varies. Thus, the new knowledge gained by examining the achieved participation would provide insight into the changes that need to be made in a comprehensive approach to children with cerebral palsy and participation-based therapy. Finally, by considering the possibilities of promoting the participation of a child with cerebral palsy, guidelines could be given in selecting and planning evidence-based interventions that promote a supportive environment and encourage their active involvement.

THEORETICAL CONSIDERATIONS

Introducing the concept of participation

As a concept, participation was introduced within the ICF and its *Children and Youth Version* (ICF-CY), published by the WHO (2001, 2007).

Defined as “involvement in a life situation” (WHO, 2001), participation is interpreted in relation to activity, performance and capacity.

Activity is the execution of a task or action by an individual. Performance describes what individuals do in their current environment, including their involvement in life situations. Capacity indicates the highest probable level of functioning that a person may achieve, measured in a uniform or standard environment (WHO, 2011).

Participation, viewed in this way, represents the *societal* perspective of functioning, while activity represents the *individual* perspective of functioning. Performance is an *executive* perspective of functioning, while capacity reflects the *environmentally adjusted* ability of the individual (WHO, 2011, p. 301, 302, 307).

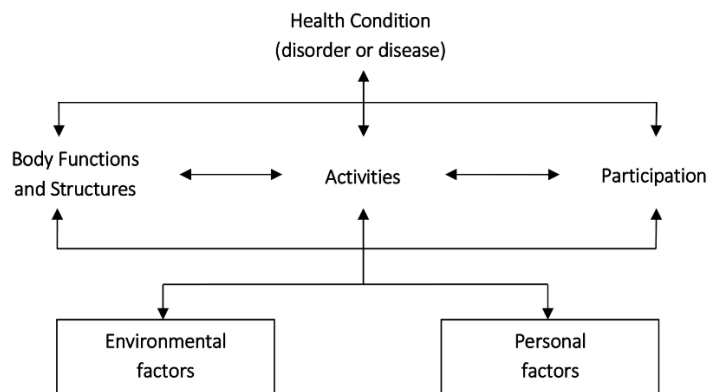


Figure 1. Interaction the between ICF model components (International Classification of Functioning, Disability and Health – ICF; WHO, 2001)¹

More specifically, the ICF model puts an individual in a context, a complex of factors that together constitute the complete context of an individual’s life (WHO, 2011). As presented, functioning and disability result from the interaction that occurs between the health condition(s) of the person and their environment. The functioning in a specific

¹ Adapted from: WHO, 2011, p. 5.

domain reflects an interaction between the *Health Condition*, on the one hand, and the *Contextual Factors* (Environmental Factors and Personal Factors), on the other hand (WHO, 2013). These interactions are bidirectional (Figure 1). The model suggests dynamic and reciprocal relations among the components (Peterson, 2005).

Health Condition is an umbrella term for diseases (acute or chronic), injuries, and disorders. Body Functions refer to the physiological functions of body systems, whereas body refers to the human organism as a whole, including the brain. Body Structures are the structural or anatomical parts of the body such as organs, limbs, and their components classified according to body systems (WHO, 2011).

The current environment is described using *environmental factors*, that is, physical, social, and attitudinal environment in which people live and conduct their lives. At the same time, the ICF model recognizes *personal factors*, for instance, age, gender and social status. These factors can affect how much an individual participates in society. Research on ICF models indicates that contextual factors play a moderating role and that they also mediate between ICF components by influencing the direction and/or strength of their association (Rouquette et al., 2015).

As stated, Contextual Factors have two components: Environmental Factors and Personal Factors and these factors constitute the context of an individual's life. It is also important to note that these factors constitute the background against which health states are classified in the ICF framework (WHO, 2011).

Environmental factors refer to the physical, social, and attitudinal environment in which people live and conduct their lives. Barriers are factors in an individual's environment that, through their absence or presence, limit functioning and create disability. Facilitators are factors in an individual's environment that, through their absence or presence, improve functioning and reduce disability.
Personal factors relate to the individual, such as age, gender, social status, life experiences, motivation and self-esteem (WHO, 2011).

The ICF model emphasized the role of environmental factors in creating disability, which made it different from *the International Classification of Impairments, Disabilities, and Handicaps – ICDH* (WHO, 1980). As explained, there are three interrelated categories of problems with human functioning in the ICF model: impairments, activity limitations and participation restrictions.

Impairments are described as "problems in body function or alterations in body structure, such as a significant deviation or loss". Activity limitations are defined as "difficulties an individual may have in executing activities" and participation restrictions as "problems an individual may experience in involvement in life situations" (WHO, 2002, p. 10).

Additionally, impairment is a loss or abnormality in body structure or physiological function (including mental functions), manifestations of dysfunction or specific decrease in body functions and structures, often identified as symptoms or signs of health conditions, yet differentiated from the underlying pathology (Peterson, 2005; WHO, 2011). However, impairment itself does not indicate a disorder or disease, because it is considered in relation to generally accepted population standards of functioning (Peterson, 2005).

Activity limitations, however, range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition. Consequently, facilitators, as environmental factors, can prevent the occurrence of participation restrictions from impairments or activity limitations, by enhancing actual performance, even though there are problems with the person's capacity (WHO, 2011).

Furthermore, there is a clear differentiation between *performance* and *capacity*. Capacity is seen through a person's capacities to perform actions, measured in a uniform or standard environment, indicating the highest probable level of functioning that a person may achieve. Accordingly, performance is seen through the actual performance of those actions in real life. By highlighting the difference between these two constructs, the effect of environment is highlighted, as well. It is possible to improve the performance by modifying the environment, and considering that environmental factors are potentially modifiable (Anaby et al., 2014), enabling environments could improve performance and participation by removing barriers and providing support (WHO, 2011).

Functioning and disability are both conceptualized within the mentioned dynamic interaction between health conditions and contextual factors. Disability is seen through an interaction among impairment, functioning, and environment, while functioning is seen as an inclusive term covering concepts of Body Functions and Structure, Activities and Participation (Peterson, 2005). Disability arises from the this interaction and refers to difficulties or dysfunctioning that an individual encounters in any of three areas of functioning: at the level of body or body part, the whole person, and the whole person in a social context (WHO, 2002, 2011).

Functioning is an umbrella term for body functions, body structures, activities, and participation, indicating the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Disability is an umbrella term for impairments, activity limitations, and participation restrictions, indicating the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Functional health implies that the person's bodily functions and body structures correspond to generally accepted standards, that the person do or can do activities of the type and to the full extent as expected from a person without any health problem,

and that the person can also develop the existence in all areas of life that are important to them, in the way that a person without impairments of body functions/structures and activity limitations would do (Camargo, 2019, p. 11). In contrast, disability implies a negative interaction between a person and the contextual factors that impacts the person's functioning and participation in specific life areas that are important to them (Leonardi et al. 2006, as cited in Camargo, 2019, p. 11–12).

The underlying conceptual framework of the ICF is based on a biopsychosocial approach. Medical and social models of disability are integrated into a unitary framework, by addressing the biological, individual, and societal perspectives of health and functioning, and not considering functional limitations only (Peterson, 2005, p. 106). In summary, the ICF is a strength-based model that illustrates a holistic approach to health. It is grounded in United Nations Conventions of the Rights of Children and People with Disabilities (UN General Assembly, 2017) and a theoretical premise of universalism. Further, the ICF uses neutral language, thus modelling an approach towards people's strengths, but also etiologic neutrality and parity. Overall, the ICF is multidimensional and comprehensive (Rosenbaum, 2019, p. 2). The ICF has set the world standard for conceptualising and classifying functioning and disability and provided a common language, terms and concepts for use (WHO, 2013).

The ICF Structure

There are two parts in the ICF structure, the first covers functioning and disability, and the second deals with contextual factors. Each part has two components (WHO, 2013).

(1) *Functioning and Disability:*

(a) *Body Functions and Body Structures*

(b) *Activities and Participation*

(2) *Contextual Factors:*

(a) *Environmental Factors*

(b) *Personal Factors*

As presented in Table 1, chapters within *Body Functions* and *Body Structures* are parallel and organized according to body systems, the component *Activities and Participation* covers domains of functioning from both an individual and societal perspective, interpreted through Capacity and Performance. *Environmental Factors* are qualified as facilitators or barriers. Various domains constitute each ICF component. Domains consist of the categories within the health and health-related domains, and these actual units of classification can be qualified in positive or negative terms. Constructs are expressed by qualifiers (Peterson, 2005). It is important to note that the ICF does not classify people. The units of ICF classification are categories within the health and health-related domains. Therefore, the ICF classifies functioning and disability (WHO, 2013, p. 18).

Table 1. *International Classification of Functioning, Disability and Health (ICF): Overview*²

Structural element	Part 1: Functioning and Disability			Part 2: Contextual Factors	
	Body Functions and Structures		Activities and Participation	Environmental Factors	Personal Factors
Domains	Body Functions (including psychological functioning)	Body Structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body function (physiological)	Change in body structure (anatomical)	Capacity: Executing tasks in a standard environment ("can do") Performance: Executing tasks in the current environment ("does do")	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Chapters	<ol style="list-style-type: none"> 1. Mental functions 2. Sensory functions and pain 3. Voice and speech functions 4. Functions of the cardiovascular, haematological, immunological, and respiratory systems 5. Functions of the digestive, metabolic, and endocrine systems 6. Genitourinary and reproductive functions 7. Neuromusculo-skeletal and movement-related functions 8. Functions of the skin and related structures 	<ol style="list-style-type: none"> 1. Structures of the nervous system 2. The eye, ear, and related structures 3. Structures involved in voice and speech 4. Structures of the cardiovascular, immunological, and respiratory systems 5. Structures related to the digestive, metabolic, and endocrine system 6. Structures related to the genitourinary and reproductive systems 7. Structures related to movement 8. Skin and related structures 	<ol style="list-style-type: none"> 1. Learning and applying knowledge 2. General tasks and demands 3. Communication 4. Mobility 5. Self-care 6. Domestic life 7. Interpersonal interactions and relationships 8. Major life areas 9. Community, social, and civic life 	<ol style="list-style-type: none"> 1. Products and technology 2. Natural environment and human-made changes to environment 3. Support and relationships 4. Attitudes 5. Services, systems, and policies 	
Positive aspect	Functioning Functional and structural integrity Activities Participation			Facilitators	Not classified
Negative aspect	Disability Impairment Activity limitation Participation restriction			Barriers-hindrances	Not classified

² Adapted from: Peterson, 2005, p. 109, and WHO, 2002, p. 16.

Discussions on the concept of participation

Participation is an actual involvement in and performance of activities in specific life situations (Granlund et al., 2012). Therefore, it is considered an objective phenomenon, meaning that a third person can observe it, although it is represented through a person's subjective experience and through an experience that is important to that person (Tuffrey, 2012). As a third qualifier, in addition to performance and capacity, it is proposed to introduce a subjective experience of involvement, which is related to the perception of engagement, motivation, enjoyment and self-efficacy. That way, the phenomenon of participation could be comprehensively understood, the importance of the subjective experience of participation further emphasized, and differentiation between activity and participation of children and youth with a disability would be clearer (Granlund et al., 2012). Incomplete differentiation and lack of clarity between the concept of *Activity* and the concept of *Participation* arises from their non-mutually exclusive definitions; at the same time, this is one of the dominant criticisms against the ICF (Fougeyrollas, 2013).

Diversity and frequency of participation are performance qualifier used to characterize participation (Granlund et al., 2012). However, participation can be conceptualised not only as involvement in life situations but also as attendance or 'being there', which is a physical or virtual presence and can be measured as the frequency of attending and/or the range of diversity of activities. Consequently, involvement can be defined as the experience of participation while attending. In summary, attendance and involvement are two essential elements of participation (Imms, 2020; Imms et al., 2016, 2017).

The concept of participation needs to be analysed in relation to the concepts most commonly associated with – physical functioning, health status, quality of life, health-related quality of life, social participation, handicap, (social) integration and (social) inclusion (Milićević, 2019a). Participation cannot simply correspond to a person's physical functioning or health status. Physical function is defined as the ability to perform basic and instrumental activities of daily living (Garber et al., 2010). Health can be considered in terms of a person's body structure and function and the presence or absence of disease or signs (health status); it is a level of health assessed by objective measures ("Health Status", 2012).

Given that participation is considered an objective phenomenon, as explained earlier (Tuffrey, 2012), it is distinct by its nature from subjective well-being because it does not reflect the individual's perspective of overall well-being and contentment in life, which includes both psychosocial and physical or health-related domains (Böling et al., 2016; Majnemer, Shevell, Law, Poulin, et al., 2008). Specifically, quality of life is an individual's perception of their position in life in the context of the culture and value systems where they live, and their goals, expectations, standards and concerns (The WHOQOL Group, 1998). Moreover, participation is distinctive from health-related quality of life because the construct of health-related quality of life includes the psychosocial dimensions of emotional, social, and role functioning (Forsyth & Jarvis, 2002; Smith et al. 1999, as cited in Varni et al., 2005, p. 592).

Although often used interchangeably, *participation* and *social participation* are not synonymous. Namely, social participation is not defined within the ICF, and no description of how these two concepts differ is given (Piškur et al., 2014). According to one interpretation, social participation reflects the performance of life habits (Fougeyrollas, 2013). Social participation implies the interaction of a person with other persons within an accessible environment, i.e. the context of school, home, community, etc. These can be parents, teachers, peers, classmates, siblings, other family members, friends.

Another criticism of the ICF concerns the definition of participation; it is considered not to sufficiently encompass social or societal involvement (Piškur et al., 2014). Based on a systematic review of the literature on the meaning and definition of social participation, Levasseur et al. (2010, as cited in Piškur et al., 2014, p. 213) concluded that social participation can be defined as “a person’s involvement in activities that provide interaction with others in society or the community”. Besides, these authors emphasized that involvement ranged from relatively passive to very active and that social participation can be viewed as both an objective and a subjective outcome. In the case of children, the evaluation of social participation should include measuring the extent to which environments or contexts are accessible and positive facilitators of child development (Chen & Cohn, 2003, p. 63). In this way, social participation allows the establishing and maintaining of social relations. In one research, it was operationalized as a person’s active engagement in activities performed formally and informally with their friends, instructors, teachers, co-workers, or other non-family members (Kang, 2010, p. 2). For example, the ICF-CY (WHO, 2007) recognizes interaction with other people and emphasizes it in several categories, such as categories in the domain dedicated to interpersonal interactions or in the domain that includes categories of community life, social and civic life.

Furthermore, it can be argued that integration and inclusion are synonyms for participation. In the concept of social integration, in general, a person is placed in a standard environment, without this context necessarily being transformed during integration. Through social inclusion or the so-called inclusive approach, the physical or social environment, with its characteristics, achieves a universal design that will provide everyone with access to equal social participation. The focus is, therefore, on setting the context and on what is being done for people with disabilities. Participation, as well as social participation, is essentially related to a person’s activities. Nevertheless, these concepts can be considered as quality indicators of environmental factors that determine the social participation of these individuals (Fougeyrollas, 2013).

Besides, participation is considered a positive term that replaces the term *handicap* used in the previous version of the classification, i.e. in the ICIDH (WHO, 1980, as cited in Fougeyrollas, 2013, p. 2). According to this model, disability is medically oriented, primarily towards adults, and the handicap is patient-focused (Gaebler-Spira, 2016). The linearity of the model is visible through the explanation of handicap through the impact that impairment and disability have on a person’s role in society or a lack of experience in fulfilling certain social roles (Gaebler-Spira, 2016).

After that, as a central concept in ICF, participation is a kind of indicator of the changes that have been made by the transition from the medical to the biopsychosocial model of disability. Instead of the causes, the focus is on the impact of the disability on everyday life. The traditional, medical model is evident in the component focused on bodily impairment, while the social model is visible through the participation restrictions that occur due to the society's construction of difficulties. The activity, on the other hand, is set up to bridge these two components (Figure 1). Participation is, as a component, the contribution of a social model of disability. That way, it is outlined that participation restrictions are socially constructed. In addition, participation is described through equality in the frequency of attending the situations as others and equal opportunities to perform the same activities as others (Maxwell, 2012, p. 38–39).

Generally speaking, the concepts of participation and social participation speak in favour of the justification of the changes that began in the last decades of the 20th century. These changes ranged from the perspective of segregation, protection, and emphasis on special needs to the perspective of the fundamental human rights of individuals whose physical, functional, and behavioural differences were considered deviant from normal standards or considered threatening to the community (Fougeyrollas, 2013).

As mentioned, optimizing participation is a primary goal of rehabilitation services and an outcome desired by parents (Arakelyan et al., 2019; Bedell et al., 2011, 2013; Coster & Khetani, 2008; Palisano et al., 2012). Moreover, optimal participation may have a positive influence and long-term benefits for quality of life, and emotional and psychosocial well-being (Kang et al., 2014). However, there is a question of the operationalization of this construct. Namely, the operationalization of participation is a topic as old as the ICF, and one of the problems is the insufficiently clear differentiation of activities and participation (Adolfsson, 2011; Coster & Khetani, 2008; Imms et al., 2016, 2017). The authors believe that criticism should be directed at the (in)clarity of the overall concept, which causes inaccuracy and inconsistency in scientific and professional reports.

Research interest in participation in disability studies is extensive, due to the potential measurability of participation (Milićević, 2019). Specifically, it is possible to measure risk factors and monitor the outcomes of therapeutic interventions, which, at the level of lived and shared experience, would confirm the benefits of those services that are not aimed at changing disability, but to change its consequences (Forsyth & Jarvis, 2002). Therefore, any definition of therapeutic goals is questionable, as well as any creation of measurement instruments that would assess participation (Coster & Khetani, 2008; Imms et al., 2016). Inconsistency in the initial definition of the term and consequent selection of measuring instruments has been observed earlier (Adair et al., 2015; Imms et al., 2016),

The question may be asked how to optimize participation. This is one of the questions whose answer is sought in contemporary theoretical and empirical considerations of participation. First, it is considered that quality, not quantity, is what makes the experience of participation optimal (Kang et al., 2014). After all, in one of the proposed multidimensional models, optimal participation is defined as “a subjective, personally determined construct, related to the meaning that is associated with and derived from

an individual's physical, social, and self-engagement in activity and life situations" (Palisano et al., 2012, p. 1042). As presented in the conceptual model, optimal participation of children with physical disabilities comprises of physical, social and self-engagement dimensions and is determined by attributes of the child, family and environment (Kang et al., 2014, p. 1736). The literature also provides clear distinctions between these terms.

First, physical engagement is the involvement of a child in activities; that is, the child is actively taking part in an activity as much as a child wants to or is able to. Secondly, social engagement encompasses interpersonal interactions that occur during activities, but also when the child is feeling included (belonging). Next, self-engagement refers to a child's enjoyment (a positive experience derived from participation), self-determination (control and choice of activities of interest, and experiencing the consequences of these decisions), and self-understanding (learning new things and developing a sense of self-concept). This dimension emerges from the involvement in the activity (Kang et al., 2014; Palisano et al., 2012).

Determinants of participation, on the other hand, include attributes of the child, family and environment. Child-related attributes refer to a combination of personal factors and body functioning factors, whereas family-related attributes cover family socioeconomic status, family ecology and functioning, and activity orientation. Finally, supportive physical environment, social and attitudinal environments and services together create environmental attributes that may promote optimal participation through the provision of physical assistance, guidance or activity opportunities (Kang et al., 2014).

What we need to know about cerebral palsy?

As a permanent, heterogeneous condition with different clinical presentations and associated conditions, cerebral palsy is often associated with life-long and multiple disabilities. Cerebral palsy affects the functioning of a person in all domains of everyday life and increasing the risk of lower quality of life and reduced participation in activities (Badia et al., 2016; Beckung & Hagberg, 2002; Michelsen et al., 2009; Milićević, 2020; Monbaliu, De Cock, et al., 2017; Palisano, Orlin, et al., 2011; Vles et al., 2015).

In a clinical picture of cerebral palsy, an injury to the developing central nervous system goes beyond the motor tracts, causing comorbidity in the form of various intellectual or sensory impairments (Johnson, 2002). Over the years, comorbidities and associated conditions, such as disturbances of sensation, perception, cognition, communication and behaviour, epilepsy, and secondary musculoskeletal problems, become as important as a motor disorder in most cases, having broad implications for planning and providing services (Johnson, 2002; Rosenbaum, 2003).

Cerebral palsy is the most frequent cause of severe physical disability or motor impairment in childhood with implied multidisciplinary rehabilitation strategies and management that should be aimed to improve daily activity and quality of life, as suggested by ICF (Monbaliu, Himmelmann, et al., 2017). Consequently, continuous heavy

demands on health, educational, and social services, as well as on families and children themselves, make service support and environmental modifications necessary for persons with severe cerebral palsy (Arneson et al., 2009; Cans, 2000).

History and definitions

The first known descriptions of cerebral palsy date back to the 5th century BCE and Hippocrates. In his “Corpus Hippocraticum”, Hippocrates discussed on the association between the prematurity, congenital infection, and prenatal stress and the pathogenesis of brain damage (Panteliadis & Vassilyadi, 2018). Cerebral palsy existed in the Ancient World. Signs are detected in representational art, literary sources and paleopathology (Panteliadis et al., 2013). Some examples are encountered in findings on the ancient civilizations, including the Egyptians, Greeks, and Romans, including the term “palsy” with certain roots in Ancient Greece (Panteliadis & Vassilyadi, 2018).

It was not until the early 19th century that concrete examples and definitions of cerebral palsy did emerge. The first descriptions of cerebral palsy date from 1843 and are accredited to William John Little and his nine lectures entitled “Deformities of the Human Frame” and published in *The Lancet* (Little, 1843, 1844). William John Little was an English orthopaedic surgeon who underwent successful correction of his equinus deformity caused by childhood poliomyelitis (Blair & Cans, 2018; Pakula et al., 2009; Panteliadis & Vassilyadi, 2018). After William John Little, spastic diplegia was called “Little's disease”. In 1861, he defended his theory that abnormal parturition, difficult labours, premature birth and asphyxia neonatorum were the cause of the severe mental and physical condition, particularly regarding deformities and classified spastic rigidity as hemiplegic, paraplegia, and generalized rigidity (Panteliadis & Vassilyadi, 2018).

The term ‘cerebral palsies’ is attributed to William Osler, a Canadian physician, who published a book entitled “The Cerebral Palsies of Children” in 1888 (Panteliadis & Vassilyadi, 2018). He confirmed the association of cerebral palsies and seizures with difficult labour, asphyxia neonatorum, prolonged resuscitation, intracranial haemorrhage and jaundice in infancy, adding that the pathological changes were, in most cases, necrotic, and not inflammatory.

By the end of the 19th century, Sigmund Freud contributed to cerebral palsy as the third major personality in the field, writing many articles on the subject (Pakula et al., 2009). According to Panteliadis and Vassilyadi (2018), Sigmund Freud advanced the knowledge by being the first to develop a classification system based on the aetiology of cerebral palsy: congenital (ante partum), acquired during birth (intra partum) and acquired postnatally (post partum). This classification system is still in use today. Secondly, he described the relationship between the location of the lesion and the degree of the contracture, indicating that the more superficial lesions were more likely to affect the lower extremities. Thirdly, he described in details various movement disorder syndromes in children and noted that many other neurologic conditions in children with cerebral palsy, such as intellectual disabilities, visual impairment, and epilepsy (Pakula et al., 2009;

Panteliadis & Vassilyadi, 2018). No less important, Sigmund Freud recognized multiple pregnancies as a risk factor for cerebral palsy (Colver et al., 2014).

One of the frequently cited definitions dates from 1964 and defines cerebral palsy as a “disorder of movement and posture due to a defect or lesion of the immature brain” (Bax, 1964, p. 295).

This definition, as the author further stated, excludes those disorders of posture and movement that are not permanent, that occur as part of progressive disease or that are solely a consequence of a mental deficiency. However, in the decades that followed, there was a need to include heterogeneity of the disorder in the definition of cerebral palsy. During the next following decades, regular international meetings devoted to the state of the art in the epidemiology of cerebral palsy have been held: in California in 1987, in Cambridge in 1989 and Brioni, Yugoslavia, in 1990 (Mutch et al., 2008).

At the international meeting dedicated to the situation in the epidemiology of cerebral palsy held in 1990 (Brioni, Yugoslavia), certain changes were made. This is one of the most commonly used definitions, both in research studies and in clinical practice (Mutch et al., 2008).

Cerebral palsy is defined as “an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development” (Mutch et al., 2008, p. 549).

Furthermore, relying on the initial definition and taking into account the emerging need for a comprehensive and multidimensional approach, Bax et al. (2005) have proposed a new and updated definition.

“Cerebral palsy describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder” (Bax et al., 2005, p. 572).

The newly proposed definition relied on the latest findings and the availability of new knowledge about the neurobiology of developmental brain injury, including modern brain imaging, the more precise measuring instruments of patient performance, and the results on the efficacy of therapy for the consequences of cerebral palsy.

As a result of cooperation between fourteen national centres and registries of eight countries within Europe, a consensus was reached and the Working Group of the Surveillance of Cerebral Palsy in Europe (SCPE) adopted a definition of cerebral palsy that

relies on phenomenology as a criterion, i.e. clinical picture and anamnestic data (Cans, 2000). For epidemiologic surveillance, five key elements were included.

“Cerebral Palsy is a group of disorders i.e. it is an umbrella term; it is permanent but not unchanging; it involves a disorder of movement and/or posture and of motor function; it is due to a non-progressive interference/lesion/abnormality; this interference/lesion/abnormality is in the developing/immature brain” (Cans, 2007, p. 818–819).

The definition explicitly excludes progressive motor functioning disorders, which are further defined as a loss of previously acquired abilities during the first five years of life. Among other things, it should be mentioned that the age of five is considered optimal for confirming the diagnosis (Cans et al., 2007, p. 36).

In 2004, an International Workshop on the Definition and Classification of Cerebral Palsy was held in the United States (Bethesda, Maryland, July 11–13, 2004). It has been agreed that cerebral palsy describes:

“... a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum et al., 2007, p. 9)

The 2007 revision contributed to changes in the perception of cerebral palsy. Namely, in this revised version, cerebral palsy was identified through disorders of the movement and posture. This way, the developmental basis of this neurodevelopmental disorder is emphasized more clearly, as well as the potential impact of motor development disorders on other aspects of the child's development.

It is important to note that, over time, many of the secondary problems become more functionally significant than the motor limitations by which cerebral palsy is primarily described. Thus, it can be concluded that the developmental perspective is a key element of the definition of cerebral palsy, from a clinical perspective (Rosenbaum, 2009, pp. 28–29).

As Pakula et al. (2009) have noted, the following four core components are common to all definitions of cerebral palsy: “(1) it is a disorder of movement and posture; (2) it results from an abnormality in the brain; (3) it is acquired early in life; and (4) the condition is static at the time of recognition” (p. 427). Moreover, the dynamic concepts of impairment and limitation of activity were introduced, and it was pointed out that cerebral palsy was frequently showing accompanying impairments (Bax et al., 2005).

Classification

Conventional terminology used to describe cerebral palsy is considered less precise and reliable (Rosenbaum, 2003). Cerebral palsy is a condition that has a variable effect on the whole body (Beckung & Hagberg, 2002).

The terms hemiplegia, diplegia, triplegia and quadriplegia primarily refer to the topographic distribution that predominates the clinical picture. As highlighted, all subtypes of cerebral palsy have a common abnormal pattern of movement and posture and differ according to topography.

Hemiplegia (hemiparesis) – predominantly implies unilateral impairment of the upper and lower extremities (arm and leg) on the same side,

Diplegia – primarily defined as a motor impairment of the lower extremities (legs; diplegia usually involves some relatively limited involvement of arms),

Triplegia – implies three limb involvement, and

Quadriplegia (tetraplegia) – implies all four limbs impairment, i.e. the whole body is functionally compromised (Rosenbaum, 2003).

Descriptions of the predominant motor disorder refer to spastic, dystonic, athetotic, and ataxic characteristics. Topographic classification is restricted to the spastic group. Physiologic classification, on the other hand, classifies cerebral palsy into two main physiologic groups, pyramidal and extrapyramidal cerebral palsy.

Pyramidal cerebral palsy – includes cases of spasticity, a clinical sign manifested by increased resistance of a limb to an externally imposed joint movement that is consistent, persistent and remains during quiet periods and sleep, and without much variation during the active state and emotional stress or irritability, and

Extrapyramidal cerebral palsy – involves cases of chorea, athetosis, dystonia, ataxia, implying involvement of all the extremities, with the upper extremities usually being more functionally affected than the lower ones, however, without the need for further topographic classification due to 4-limb involvement, with upper extremities typically being functionally more involved than the lower extremities; there is more tone variability during relaxation and sleep, especially in stressful situations (Pakula et al., 2009).

While the classic descriptor of spasticity is the “clasp knife”, meaning that rapid passive movement at a joint evokes spastic hypertonus, extrapyramidal hypertonicity is usually described as “lead pipe” rigidity. This phenomenon is further explained as an increased tone persisting throughout slow passive flexion and extension of an extremity (Pakula et al., 2009).

A unique European classification of cerebral palsy has been adopted to set clear inclusion and exclusion criteria for epidemiologic surveillance. Hierarchical classification tree distinguishes cerebral palsy sub-types (Cans, 2000, p. 821).

Cerebral palsy is classified into three main groups relying solely on the clinical features, i.e. clear neurological signs as indicators of the pathology of the cerebral motor system: spastic, ataxic, dyskinetic (Cans et al., 2007). Mixed forms should be classified according to the dominant clinical characteristic (Cans et al., 2007).

Together with the topographic distribution, a simple and now widely used classification of four subtypes was proposed: unilateral spastic, bilateral spastic, dyskinetic, and ataxic (Cans, 2000).

Spastic cerebral palsy is characterized by at least two of the following three clinical signs: an abnormal pattern of posture and/or movement; increased tone (not necessarily constant); pathological reflexes (increased: hyperreflexia and/or pyramidal signs, e.g. Babinski). Spastic cerebral palsy can be bilateral or unilateral.

Bilateral spastic cerebral palsy is diagnosed if the extremities on both sides of the body are affected. Unilateral spastic cerebral palsy is diagnosed if the extremities on one side of the body are affected.

Ataxic cerebral palsy is dominated by an abnormal pattern of posture and/or movement and loss of muscle coordination, which is why movements are performed with abnormal force, rhythm and precision.

Dyskinetic cerebral palsy is characterized by an abnormal pattern of posture and/or movement and involuntary, uncontrolled, repetitive, and sometimes stereotyped movements. Dyskinetic cerebral palsy may be dystonic or choreoathetotic.

As dominant features, hypokinesia (reduced activity) and hypertonia (increased tone) occur together in dystonic cerebral palsy. In choreoathetotic cerebral palsy, hyperkinesia (increased activity) and hypotonia predominate (decreased tone; Cans, 2000, p. 821). Chorea refers to rapid, abrupt, involuntary, and often intermittent movements, while athetosis refers to slower and constantly changing, writhing, or contorting movements (Cans et al., 2007, p. 36).

Relying on the hierarchical classification tree of cerebral palsy sub-types and comparing the data gathered in population-based studies in Europe, Western and South-east Australia, Quebec (Canada) and Atlanta (United States), the group of authors concluded that percentages of cerebral palsy subtypes were similar between regions (Cans et al., 2008). The proportion of bilateral spastic cerebral palsy ranged from 44% to 56% of all registered cases, including postneonatal, while unilateral spastic cerebral palsy occurred in 23% to 39% of cases. Dyskinetic cerebral palsy was found in 1% to 8%, ataxic in 3% to 21%, and mixed in 1% to 9% of cases. The same authors observed that the percentage of

children with more severe motor impairments (GMFCS³ level IV/V and/or BFMF⁴ level IV/V) ranged from 23% to 35% of all reported cases according to the results from Australia, Norway, Sweden and France. Furthermore, dyskinetic type of cerebral palsy had the greatest level of between studies, which, according to the authors, indicated possible problems in the classification of the mixed form (Cans et al., 2008).

When data on cerebral palsy subtypes from 13 regional centres in Europe for birth years 1980 to 1990 was analysed, bilateral and unilateral spastic subtypes were the most common ones (54.9% and 29.2%, respectively). Dyskinetic cerebral palsy contributed only to 6.5% of cases, only 4.3% had ataxic subtype, whereas 3.7% were unclassified (Johnson, 2002). The spastic form is a dominant subtype according to the numerous national population-based reports and other scientific reports worldwide (Al-Asmari et al., 2006; Andersen et al., 2008; Arneson et al., 2009; Beckung et al., 2008; Colver et al., 2012; Delacy & Reid, 2016; Demeši Drljan, 2011; Galea et al., 2019; Himmelmann et al., 2006; Johnson, 2002; Nordmark et al., 2007; Smithers-Sheedy et al., 2016; Surman et al., 2006; Yim et al., 2017).

Prevalence

There are no precise and unique data on the prevalence of cerebral palsy. In the literature, prevalence range from 1.9 to 4.4 per 1,000 births (Himmelmann, 2006; Pakula et al., 2009; Serdaroğlu et al., 2006). Cerebral palsy occurs in 2 to 3 per 1,000 live births across Europe (Cans, 2000). In Western countries, a total of 2 to 2.5 of every 1,000 live-born children have cerebral palsy (Rosenbaum, 2003). When information on over 6000 children with cerebral palsy from 13 geographically defined populations in Europe for the period 1980 to 1990 was analysed, the overall rate of 2.08 (95% CI 2.02–2.14) per 1,000 live births was calculated (Johnson, 2002).

More specifically, it is reported that the prevalence rate in Europe ranges from 1.5 per 1,000 live births in Scotland, United Kingdom, to 3 per 1,000 live births according to data from East Denmark (SCPE, 2000). Thus, the prevalence of 2.1 per 1,000 was found in Norway (Meberg, 1990), 2.4 in both Malta and Sweden (Hagberg et al., 1996; Sciberras & Spencer, 1999), and 2.5 in Finland (Riikonen et al., 1989). The reported rates are 1.6 per 1,000 live births in China (Liu et al., 1999) and 4.4 in Turkey (Serdaroğlu et al., 2006).

For comparison, at the level of the population of children born between 1993 and 2006 in the territory of three of the six federal states of Australia (South Australia, Victoria, Western Australia), a combined rate of 2.1 per 1,000 live births was found (95% CI 1.9–2.1). When only cases with a presumed pre/perinatally acquired brain injury or maldevelopment, a birth prevalence was 2.0 (95% CI 1.9–2.1) (Smithers-Sheedy et al., 2016). Arneson et al. (2009) reported an average prevalence of 3.3 per 1,000 (95% CI 2.9–3.8) in the 2004 population of eight-year-olds living in the three sites of the United

³ GMFCS = Gross Motor Function Classification System

⁴ BFMF = Bimanual Fine Motor Function

States (north-central Alabama, metropolitan Atlanta, south-central Wisconsin). The incidence of cerebral palsy in China ranges between 1.8 ‰ and 4 ‰, with an average of 3.25‰ recorded in 2011 (Wu & Liu, 2014). The first meta-analytical study on the prevalence of cerebral palsy, which included 29 studies published worldwide, reported an overall prevalence of 2.11 (95% CI: 1.98–2.25) per 1,000 live births (Oskoui et al., 2013).

Official data related to cerebral palsy, as well as national or regional registers of persons with cerebral palsy, are not available in the Republic of Serbia (Demeši Drljan, 2011; Milićević & Simeunović, 2020). It is estimated that in Serbia, in the population aged three to 18, for every thousand, two persons have cerebral palsy, giving a total number of over 10,000 on the territory of the Republic of Serbia around 2,000 people with cerebral palsy in Belgrade (Savić et al., 1997). It is also estimated that 150 new cases of cerebral palsy are diagnosed in Serbia every year (Krunić Protić & Lazović, 2015).

The prevalence of cerebral palsy per 1,000 live births in AP Vojvodina for the period from 1990 to 2009, and the average rate is 0.65; in the mentioned period, 206 new cases of cerebral palsy were registered on the territory of AP Vojvodina (Demeši Drljan, 2011). As further stated in this scientific report, the 2005 revision showed a rate of 1.89 per 1,000 live births, comparable to data from other countries. In general, in the period from 1991 to 2001, there was a tendency of a slight decrease in the prevalence of cerebral palsy, most likely due to changes in antenatal and neonatal care. Until 2009, there was an increase in prevalence caused by a combination of various factors (increase in the number of premature newborns, poor socio-economic conditions, late implementation of modern perinatal and neonatal care compared to more developed countries, better organization and management of medical records).

Associated conditions and disorders

The functional difficulties that are collectively referred to as associated disorders in cerebral palsy are not primarily related to mobility but a lesion of the central nervous system. In other words, an injury to the developing central nervous system goes beyond the motor tracts, which explains various comorbidity in a clinical picture of cerebral palsy (Johnson, 2002). Comorbidities and associated conditions, such as disorders of sensation, perception, cognition, communication and behaviour, epilepsy, and secondary musculoskeletal problems, are as important as a motor disorder in most cases, with far-reaching implications for planning and providing services (Johnson, 2002; Rosenbaum, 2003).

Nearly all individuals with cerebral palsy have one or more comorbidity, whereas one-half have at least one comorbidity attributed to the same cause, complications, and coincidentally co-occurring with cerebral palsy (Hollung et al., 2019). Savić (2002, as cited in Nedović et al., 2012, p. 65) considers this group of disorders as manifestations of parallel neuromotor disorders. The functional difficulties include sensory, cognitive, behavioural and other developmental disorders, as well as epilepsy, feeding difficulties due to problems with chewing and swallowing, irritability and irregular sleep patterns.

These disorders can be observed in the earliest development (Rosenbaum, 2003). The number of problems with learning and/or understanding is higher as the level of disability increases (Demeši Drljan, 2011; Wong et al., 2012).

Following the research questions on relationship between the overall profile of motor abilities of children with cerebral palsy and their need for assistance in everyday activities, it was found that gross motor and manual abilities determined largely the functional independence level in self-care and mobility (Milićević, 2020). As stated earlier, various functional limitations of different severity restrict or even unable active involvement of persons with cerebral palsy in daily activities (Beckung & Hagberg, 2002).

Planning and implementation of uniform systemic solutions are challenging and impractical, whether they are related to health care, rehabilitation, education or social equity. Due to the diversity of clinical characteristics of cerebral palsy, each case is different (Milićević, 2020; Monbaliu et al., 2016; Monbaliu, Himmelmann, et al., 2017). The heterogeneity of the clinical picture implies multidisciplinary strategies and continuous management aimed to improve daily activities, participation and overall life quality (Monbaliu, De Cock, et al., 2017; Monbaliu, De La Peña, et al., 2017; Monbaliu, Himmelmann, et al., 2017).

The SCPE collaborative group, additionally to the European Classification, singled out data on the following four associated disorders as recommended for defining and classifying cerebral palsy, and when forming a cerebral palsy database or register. The following associated disorders are included: intellectual impairment, visual and hearing impairment, and epilepsy (Cans et al., 2007, p. 37).

Intellectual impairment is classified according to the thresholds of cognitive impairment as given by the World Health Organization (WHO): (a) Normal: IQ > 85, attendance of regular school without support, (b) Borderline: IQ 70–84, (c) Mild impairment: IQ 50–69, some basic literacy and numeracy achieved, (d) Moderate to severe impairment: IQ 20–49, (e) Profound impairment: IQ < 20.

Visual impairment is defined in terms of visual acuity (< 0.1 in both eyes after correction), while the severity of hearing impairment is determined by hearing loss (more than 70 dB in the better ear before correction).

The presence of epilepsy implies two unprovoked seizures, with neonatal convulsions excluded (Cans et al., 2007, p. 37).

In South Korea, about 30% of children with cerebral palsy have an intellectual disability, defined as a significant delay in cognitive development, or diagnosed by a formal intelligence test (Yim et al., 2017). None or mild intellectual impairment (IQ > 70) are observed in 47% of children with cerebral palsy, while other data indicate that IQ > 70 occurs in 49% of cases (Colver et al., 2012; Dang et al., 2015). Normal (IQ > 90) and borderline intellectual functioning (IQ > 70) were found in 33% and 14% of children with cerebral palsy, respectively, in an epidemiological study conducted in Sweden for the birth year period 1990 to 1993 (Nordmark et al., 2007). For comparison, the results from

Israel show a slightly different distribution: normal intelligence was found in 22% of children with cerebral palsy, borderline intelligence in 17%, mild intellectual disability in 22%, and moderate and severe in 24% and 15% of children examined, respectively (Gabis et al., 2015).

According to the results of population-based studies, the proportion of children with cerebral palsy with intellectual disability (IQ < 70) ranges from one- to two-third of cases (Andersen et al., 2008; Delacy & Reid, 2016; Pakula et al., 2009). Severe Intellectual impairment (IQ < 50) occurs in one-third of children with cerebral palsy (Beckung et al., 2008; Cans et al., 2008; Colver et al., 2012; Dang et al., 2015; Johnson, 2002). The rate of severe intellectual deficit among children with cerebral palsy born 1980 to 1990, defined as IQ < 50, is 0.61 per 1,000 live births (Johnson, 2002). Learning disability occurred in 40% of children with cerebral palsy aged four to eight years, that is, mild in 14% and severe in 26% (Himmelmann et al., 2006).

Based on the clinical picture of 1,129 preschool and school-aged patients with cerebral palsy who were examined by an expert team at the then Institute for Cerebral Palsy and Developmental Neurology in Belgrade, Savić et al. (1997) made several observations. According to the data, the largest number of patients was classified in the category of mild intellectual disability (27.1%), then in the category of normal average (18.7%), borderline (11.4%) and normal below-average intellectual abilities (9.7%). Generally, different levels of intellectual disability were confirmed in 50.9% of the sample (moderate in 9.2%, severe in 5.0% and profound in 9.6% of patients). Intellectual status was confirmed in 32% of a total of 136 respondents in a published study on risk factors and characteristics of cerebral palsy in the territory of AP Vojvodina (Demeši Drljan, 2011). In a sample of 35 subjects with cerebral palsy aged four to six years (of whom 31 subjects had a spastic form), more than 50% had a reduced level of intellectual functioning (Radulović et al., 2015).

As reported by Bax et al. (2007), in a sample of 350 people with cerebral palsy, visual problems were detected in 42% of cases, although there are problems in detection and the actual proportion is probably higher. According to the results of other studies, 4.4% of children with cerebral palsy have a severe visual impairment, and 17.0% have mild to moderate (Demeši Drljan, 2011). Blair & Smithers-Sheedy (2016) stated that some form of visual impairments was detected in almost half (46%) of cases of prenatal and perinatally caused cerebral palsy, 4.9% were blind, 28% had minor visual impairments, while 14% had manifested strabismus. Moreover, manifest strabismus was more prevalent in higher GMFCS levels, i.e. in cases with more severe levels of motor impairment (Blair & Smithers-Sheedy, 2016).

The results of epidemiological studies show that the proportion of children with cerebral palsy with co-occurring visual impairment ranges from 2% to 19% (Pakula et al., 2009, p. 443), and up to 22.2% (Nordmark et al., 2007). However, population-based data from Australia for children born 1996 to 2005 revealed that 36% of cases had some degree of visual impairment and 6% had functional blindness, with the highest prevalence in spastic quadriplegia (16%) and the increasing proportions of visual impairment and functional blindness detected with increasing GMFCS level (Delacy & Reid, 2016).

Other authors reported that 19% of children with cerebral palsy aged four to eight years have a severe visual impairment (Himmelman, 2006), 19% at the age of four to eight years (Himmelman et al., 2006) and 33.6 % at the age of seven to 18 (Milićević, 2016). Ophthalmologic impairment, as one of the accompanying impairments, was present in one-third (32.9%) of 773 subjects with cerebral palsy aged between 1 year and 23 years (Yim et al., 2017).

Visual impairment was overall present in 48.7% of children with spastic of cerebral palsy aged five to 18 years (Glinac et al., 2015), whereas low visual acuity was found in 71% of children with cerebral palsy aged between six months and 19 years (Schenk-Rootlieb et al., 1992). Over one in 10 children (11.1%) had severe visual impairment, defined in case of visual acuity less than 0.3 in the better eye after correction or 'blind', giving the rate of 0.23 per 1,000 live births (Johnson, 2002). Vision characterized as blindness or no useful vision was confirmed in 7% (Beckung et al., 2008).

The prevalence of hearing problems ranges from 2% (Beckung et al., 2008; Himmelman, 2006) to 7% (Bax et al., 2007). The results of epidemiological studies show that the percentage of hearing loss ranges from 2% to 6%, as well (Pakula et al., 2009, p. 443). In South Korea, hearing impairment was found in 2.6% of cases (Yim et al., 2017). Hearing problems were reported in 2.6% of children with spastic cerebral palsy aged five to 18 years (Glinac et al., 2015). Hearing impairments of varying degrees were registered in 3.6% of children with cerebral palsy aged seven to 18 years (Milićević, 2016), and severely impaired hearing was reported for 4% of 294 children with cerebral palsy (Andersen et al., 2008). In the population-based data from Australia, 12% of children with cerebral palsy had some degree of hearing impairment and 3.5% were deaf bilaterally, with the highest prevalence in dyskinetic subtype (21%) and the increasing proportions of hearing impairment and bilateral deafness detected with increasing GMFCS level (Delacy & Reid, 2016).

Based on the results of epidemiological studies, it can be noted that the proportion of children with cerebral palsy with co-occurring epilepsy ranges from 18% to 46% (Beckung et al., 2008; Himmelman et al., 2006; Nedović et al., 2012; Nordmark et al., 2007; Pakula et al., 2009; Surman et al., 2006; Vles et al., 2015; Wake et al., 2003; Wong et al., 2012; Yim et al., 2017). Furthermore, based on data from eight European registries, epilepsy occurs in 20% to 28% of cases (Colver et al., 2012; Dang et al., 2015). Other authors reported a rate of 0.34 per 1,000 live births (Johnson, 2002) or a cumulative representation of 33% to 35% (Beckung & Hagberg, 2002; Gabis et al., 2015; Himmelman, 2006). The prevalence can vary from 16% in spastic diplegia to 50% in spastic quadriplegia (Bax et al., 2007), or 28% when only the spastic form of cerebral palsy is examined (Glinac et al., 2015). Epilepsy occurs in 94% of children and adolescents with spastic tetraplegic cerebral palsy with severe cognitive impairment (Edebol-Tysk et al., 1989). Later, a decrease in the prevalence of epilepsy over the decades was reported (Sellier et al., 2012). The proportion of CP cases with epilepsy in Australia from 1996 to 2005 (27.8%) (Delacy & Reid, 2016) was similar to the proportion reported for the period between 1999 and 2004 (28%) (Reid et al., 2011). The literature review has confirmed that it is most common in quadriplegia, followed by hemiplegia and tetraplegia (Pakula et al., 2009, p. 442), although reports on lower proportions can be found in the literature.

For example, active epilepsy was confirmed in 28% of children with cerebral palsy aged two to ten years (Andersen et al., 2008) and 34% of children with cerebral palsy aged 1.8 to 15.4 years, yet it was mainly prevalent in quadriplegia (24%) (Gabis et al., 2015). Epilepsy was present in 25.5% of children with cerebral palsy in Serbia (Milićević, 2016), whereas 33% was noted in AP Vojvodina (Demeši Drljan, 2011). Earlier, Milenković (1997) reported that epilepsy was found in 27% of a total of 115 subjects with cerebral palsy aged three to ten years and that it most often manifests in cases of pyramidal tract lesions.

Speech-language disorders are included among accompanying disorders. Almost every other child with cerebral palsy (44%) has a speech-language delay (Yim et al., 2017). While normal speech is confirmed in more than a half (57%) of the cross-European sample of children with cerebral palsy ($n = 818$), 15% had no formal communication (Colver et al., 2012). In the same study, 16% of cases were using speech with difficulties, and 12% was using nonspeech for formal communication, all confirmed in the follow-up study (Dang et al., 2015). Comparable results were reported earlier in Norway (Andersen et al., 2008). In dyskinetic cerebral palsy, 80% of cases with anarthria used augmentative and alternative communication (Himmelmann, 2006). According to data from the Australian Cerebral Palsy Register on 3466 children born from 1996 to 2005, speech impairment was present in 61% of cases and almost 24% were essentially non-verbal at 5 years of age (Delacy & Reid, 2016). Concerning the subtypes of cerebral palsy, hypotonia (95%), dyskinesia (94%), and spastic quadriplegia (89%) showed the highest proportions of speech impairment (89%–95%).

Intellectual disability, severe visual impairments and epilepsy are among the most common associated disorders in a clinical picture of cerebral palsy (Nordmark et al., 2007), followed by disorders in communication (Milićević & Krstić, 2016). In the clinical picture of cerebral palsy, the proportion of these three accompanying increases significantly with GMFCS levels (Delacy & Reid, 2016; Himmelmann, 2006; Himmelmann et al., 2006). Moreover, increasing proportions of speech and hearing impairment are detected with increasing GMFCS level (Delacy & Reid, 2016).

When it comes to the number of severe associated impairments, more than 90% of children with spastic hemiplegia and diplegia and 86% of children with ataxia had none, or only one, severe associated impairment. On the other hand, one-half of children with quadriplegic and hypotonic subtypes of cerebral palsy had two or more (Delacy & Reid, 2016). Two or more associated disorders were reported for 73% of children with quadriplegia, 71% of children with dyskinetic cerebral palsy, 53% of children with diplegia and 40% of children with ataxic cerebral palsy. On the other hand, in 30% of children with spastic unilateral cerebral palsy, the presence of associated disorders was not confirmed. Overall, the highest percentage of children with cerebral palsy has some of the associated disorders or impairments (intellectual disability, epilepsy, visual impairment, speech impairment, hearing impairment, spinal or foot deformity). Specifically, just over one-half of cases (52%) had at least two associated diseases, while almost one-third (29.5%) and one-fifth (18.1%) had one and none-detected, respectively (Demeši-Drljan, 2011). Similarly, Beckung and Hagberg (2002) reported no additional neuroimpairment in almost one-half (47%) of children. Some authors reported that one or two

accompanying impairments can be found in one-fifth of children with cerebral palsy (Yim et al., 2017).

Generally speaking, motor function and associated impairments are stable between childhood and adolescence in young people with cerebral palsy. In a longitudinal population-based study conducted in nine European regions, 63% of cases had an unchanged level of impairment of fine motor function and 98% had an unchanged level of hearing impairment, whereas possible changes were detected for seizures and vision (Nystrand et al., 2014). A more detailed insight into the characteristics of cerebral palsy prevalence, subtypes, and associated impairments was achieved in a population-based comparison study of adults and children (Jonsson et al., 2019). As highlighted, subtype distribution, severe motor impairment, intellectual disability, and epilepsy were less common among surviving adults with cerebral palsy born between 1959 and 1978 than in the original cohort.

What does previous research tell us about the participation of children with cerebral palsy?

As a complex and multidimensional construct, participation is widely set as a starting theoretical basis for empirical research on personal and environmental factors that define it. Numerous studies show that children with disabilities, including children with cerebral palsy, are at increased risk of reduced and less diverse participation in the formal and informal daily activities, both at home, school and in the community in which they live (Bedell et al., 2013; Coster et al., 2013; Engel-Yeger et al., 2009; Imms et al., 2008, 2009; King et al., 2003; Law, 2002; Law et al., 2004, 2013; Majnemer et al., 2015; Shikako-Thomas et al., 2013, 2008). The daily life of these children is characterized by less variety and a slower tempo, they spend more time in dependent activities, in activities of personal care and quiet recreation, and less in household chores, activities that take place outside the home setting or activities that require social engagement (Brown & Gordon, 1987).

In one study, activity-specific patterns and child, family and environmental correlates of participation restriction in nine community-based activities among young children 0–5 years old with developmental delay and other disabilities in the USA were examined (Khetani, Graham, et al., 2013). Based on the perception of 1.509 caregivers, community participation is significantly and strongly associated with a child, family and environmental factors across multiple community-based activities. As specified, Khetani, Graham et al. (2013) found that 39.3% of caregivers expressed difficulties in community participation because of their child's functional limitations (behavioural, speech, mobility). Moreover, child's functional abilities, not their eligibility for early intervention services, were associated with participation difficulties across most community-based activities.

Several personal, environmental and family characteristics have been singled out as the primary determinants of participation in leisure activities of children and youth with

cerebral palsy (Shikako-Thomas et al., 2008). Increasing age, higher levels of limitations in motor functioning and lower socioeconomic status of parents expressed through family income and parental level of education, are associated with reduced participation. Gender, interests and preferences also have an effect on the choice of activities. Family functioning is related to the choice of leisure activities, but also the level of social support. Environmental determinants, such as physical ones, have a negative impact on participation through lack of equipment and structural barriers, affecting participation in the formal activities. Social environmental determinants, on the other hand, are reflected through prevailing policies, segregation, and lack of information, organization, and peer support. Environmental factors related to attitudes have a negative effect through bullying, stigmatization and adult dependence (Shikako-Thomas et al., 2008, p. 164). Later, leisure participation of adolescent with cerebral palsy is associated with factors related to their functional characteristics and attitudes, the family environment, socioeconomic status, and contextual factors, such as school type. Adolescent's preferences for activities were confirmed as strong predictors of participation in different leisure activities, except for skill-based activities (Shikako-Thomas, Shevell, Schmitz, et al., 2013).

For example, more challenging behaviour, as reported by mothers of children with cerebral palsy, was followed by a lower level of the child's involvement in home activities, and lower overall parental satisfaction with child's current home participation (Milićević, 2014). The home environment was rated as less helpful and less supportive to the child's home participation, too.

Childhood participation has far-reaching physical and mental health benefits for adolescents (Shikako-Thomas, Shevell, Schmitz, et al., 2013). Childhood participation was confirmed as the main predictor of participation in daily activities and social roles of adolescents with cerebral palsy (Dang et al., 2015). Pain, psychological problems and parenting stress predicted, in varying degrees, restricted participation at adolescence. However, these childhood factors had lower effects than impairment, which included walking ability as captured by the gross motor functioning (GMFCS level), two-handed fine motor functioning (BFMF level), seizures, feeding, communication, intellectual impairment.

Every day, families with children with disabilities face a number of challenges that can have an impact on various aspects of family life (Davis & Gavidia-Payne, 2009). Heterogeneity of developmental disorders and developmental disabilities, the fact that each child has its own unique profile of abilities and skills, and specifics of daily care activities that are time-consuming and physically demanding represent factors that interrupt family routines and change dynamics of family activities (Davis & Gavidia-Payne, 2009; Milićević, 2016; Plant & Sanders, 2007). On the other hand, families are increasingly encouraged to take an active role in health care, rehabilitation, improving social participation and quality of life, education and vocational training of their children with developmental disabilities or chronic diseases (Milićević & Klič, 2014). That way, caring for a child with developmental disabilities often burdensome and places new demands on parents who, consequently, experience higher levels of stress (Plant & Sanders, 2007). In other words, the medical, physical and functional aspects related to

the disability are not sufficient to gain a comprehensive insight into the daily life of a person with cerebral palsy, nor can they be used to assess the current situation and propose measures within the intervention program.

Numerous scientific studies have examined the motor abilities of people with cerebral palsy, the specifics of cognitive functioning, their visual, auditory and speech-language abilities and their social development. The research also included the difficulties that these people encounter during the process of schooling, working and starting a family. In the available literature, we also find research that examined various aspects of the participation of people from this population. However, the variability of environmental factors and their interaction with variable motor dysfunctions, often accompanied by various associated disorders, require additional research.

Still, the diversity of clinical characteristics makes each case of cerebral palsy a unique one, having a different impact on the life of children and their families and constantly posing new challenges in everyday clinical work. This considerable variability of motor dysfunction, combined with numerous other disorders, makes planning and implementation of uniform systemic solutions challenging and impractical, whether they are related to health care, rehabilitation, education or social equity (Milićević, 2020; Monbaliu et al., 2016; Monbaliu, Himmelmann, et al., 2017)

Orlin et al. (2010) have explored the effect that age and gross motor function have on participation in home, extracurricular, and community activities among children and young people with cerebral palsy. A total of 500 subjects were included, divided into two groups. The first group consisted of 291 children aged six to 12 years. In the second group, there were 209 young people aged 12 to 21 years. To assess diversity and intensity of participation, *the Children's Assessment of Participation and Enjoyment – CAPE* (King et al., 2004) was used. The results indicated a higher diversity and intensity of overall participation in children with cerebral palsy compared to young people with cerebral palsy. Differences were also confirmed in relation to GMFCS level, i.e. the highest level of overall participation was found in GMFCS level I, and the lowest in GMFCS level IV and V. Children with cerebral palsy showed higher levels of participation in recreational but not formal (team sports, sports clubs) or physical activities. At the same time, at the GMFCS level I, the subjects achieved the highest level of participation in physical activities. However, overall diversity and intensity are still low. As many as 12% of young people did not perform any formal activity, 14% did not perform any physical activity and 22% did not perform any skill-based activity in four months before the examination. Among children with cerebral palsy, the same percentages are 8%, 12% and 12%, respectively. Also, as the authors have emphasized, the assumption that children are more involved in formal and physical activities, and adolescents in social activities has not been confirmed (Orlin et al., 2010).

As previously reported by King et al. (2010), there are differences in diversity and intensity, i.e. frequency of participation, between children with and without physical disability. This outcome of comparisons is most noticeable, i.e. with the largest effects, in active physical (bicycling, doing a paid job, organized or free physical activities, team sports), social (hanging out, talking on the phone, going out, community events, visiting)

and skill-based activities (dancing, swimming, horseback riding, art classes, playing musical instruments). Children with physical disability participated in less of these activities and with a lower frequency, most often accompanied by close relatives. Further, social activities generally take place closer to home, as opposed to self-improvement activities (doing homework, going to the library, attending church, temple or religious activities, doing a chore, reading, shopping, writing) and skills-based activities. According to the results, the age and disability effects are most visible in the diversity of active physical activities; children without physical disability aged 12 to 14 participated in a number of these activities. The effect of the interaction of these two factors is visible in intensity, i.e. frequency of recreational activities and social activities that are most frequent in children without physical disability aged 6 to 8 years or 12 to 14 years. Besides, their immediate family accompanies children with a physical disability at aged 12 to 14, while children without physical disability mostly participate with friends. A total of 422 subjects with a physical disability and 354 subjects without physical disability participated in this study. Three age groups were monitored: younger (6–8 years), middle (9–11 years) and older age (12–14 years). The CAPE (King et al., 2004) was used to collect data on the diversity and intensity of participation, location of active physical, skill-based, and self-improvement activities, companionship as the presence of other people and the level of enjoyment.

The results of research conducted in Spain (Longo et al., 2013) confirmed lower levels of diversity and intensity, i.e. frequency versus the high level of enjoyment of participation in leisure activities outside of school in children and adolescents with cerebral palsy. Moreover, child and environmental factors determined participation more than family factors. The research was focused on patterns and predictors of leisure participation in a sample of 199 subjects aged eight to 18 years (mean age 12.11 years, $SD = 3.02$). The CAPE in Spanish (King et al., 2004) was used to assess participation in recreational and leisure activities. Regression analysis included personal factors (gender and age of children, GMFCS level, and level of intellectual disability), family factors (age, gender and educational level of caregivers, family type, number of siblings) and environmental factors (income, school type, area of domicile). Lower levels of motor and intellectual impairment, as well as attending regular instead of a special school, are associated with a higher diversity of activities in which children were involved, but also with the intensity of participation. Personal factors, as predictors, explained 43% of the variance of diversity, i.e. 40% of the variance of the intensity of overall participation. Environmental factors explained 27% of the variance of diversity, i.e. 24% of the variance of the participation intensity. These models explained a small percentage of variance in the levels of participation enjoyment, between 1% and 6% (Longo et al., 2013, p. 272).

Beckung and Hagberg (2002) have observed an association between motor function expressed through gross motor function (GMFCS), fine manual function (BFMF), as well as intellectual disabilities, with limitations participation at the age of five to eight. GMFCS was the most important prognostic factor for restrictions in mobility, IQ level was a predictor for restrictions in education and social relations, while the BFMF contributed significantly in the prediction of restrictions in mobility and social relations

According to the results of longitudinal studies, early predictors of later participation change in various areas can be observed at the earliest age (Bult et al., 2013; K. P. Wu et al., 2015), both in the domain of personal and environmental factors and within family dynamics. Family factors, according to some authors, can have an important role in participation (King et al., 2006; Palisano, Orlin, et al., 2011). The impact of family dynamics is achieved through opportunities for active involvement based on family activity orientation, family preference for recreation and family engagement in social and recreational activities, while supportive relationships for the child had indirect effects on participation. When predictors of participation in informal and formal activities outside of school were examined, Imms et al. (2009) found strong evidence that girls, children with higher manual ability and those who preferred informal activities participated in more informal activities. Participation in formal activities was directly associated with attendance at mainstream school, as an environmental factor, as well as with a preference for formal activities.

Multiple determination of the intensity of participation in leisure and recreational activities by multiple child and family determinants has been confirmed (Palisano, Chiarello, et al., 2011; Palisano, Orlin, et al., 2011). Applying structural equation modelling, 32% of the variance in intensity, i.e. frequency of participation was explained by factors related to the child, family and services. Higher intensity of participation was associated with higher gross motor function, higher enjoyment, more effective adaptive behaviour, younger age, and higher family activity orientation, but services did not influence participation (Palisano, Chiarello, et al., 2011). As highlighted, adaptive behaviour is important for participation of children with CP and is influenced by communication and family supports. However, it was shown that the relationship between the intensity of participation and the extent to which services meet the needs and with the provision of services is not statistically significant, although the provision of services was influenced by parental education and family structure and relationships. The authors have especially emphasized adaptive behaviour as important for understanding the participation of children with cerebral palsy and presented the fact that 31% of the variance in adaptive behaviour was explained by speech and communication and family structures and relationships. This study included 288 school-age children with cerebral palsy aged 6 to 12 years (mean age 9y 8mo, SD 2y).

Further, applying the same methodology to a sample of 205 older children with cerebral palsy, aged 13 to 21 (mean age 16.2, SD 2.2y), it was found that better physical abilities, younger age, female gender, higher participation enjoyment and family activity orientation were associated with higher intensity, i.e. with more frequent participation in leisure and recreational activities (Palisano, Orlin, et al., 2011). Also, the GMFCS level and parental education have been confirmed as determinants with an indirect effect, while the importance of the path between services and intensity of participation has not been confirmed.

The aim of research published by Engel-Yeger et al. (2009) was a comparison of patterns of participation of young adolescents with cerebral palsy and their typically developing peers, with a focus to the effects of cerebral palsy and gender on participation in activities outside of formal school. A total of 52 subjects aged 12 to 16 years were

included, namely 22 subjects with cerebral palsy and 30 control subjects. As an assessment tool, the CAPE (King et al., 2004) was used. According to the data, young adolescents of typical development were involved in more activities and more frequently compared to their peers with cerebral palsy. No differences were found between formal and skill-based activities in terms of diversity and intensity, which the authors have explained by their overlap in school and rehabilitation programs. Similarly, there was no difference in intensity, i.e. how often the subjects were engaged in recreational and active physical activities. In contrast, the differences between the groups were revealed in the domain of informal activities. In addition, activities in which girls with cerebral palsy participated in a higher percentage took place at home compared to peers of typical development in the domains of informal activities and overall participation. Boys of typical development, on the other hand, performed a higher percentage of self-improvement activities in the home environment than did boys with cerebral palsy. Finally, although there were no differences between groups in the level of enjoyment, girls with cerebral palsy expressed a higher level of enjoyment with self-improvement activities than did boys with cerebral palsy or peers of typical development.

Consistent findings were reported in a study conducted in Serbia (Grbović et al., 2012). Analysing the participation in leisure activities of 29 young people with cerebral palsy aged 11 to 19 years, the authors have found a low diversity of these activities, especially skill-based activities, active physical activities and social activities. Comparable to similar research by other authors, young people with cerebral palsy were involved mainly in quiet recreational and social activities, followed by self-improvement activities, while the diversity of physical activities and skills-based activities was very low. In other words, young people with cerebral palsy are more often involved in less intense and unstructured physical activities, than in sports activities or activities that require special skills. Nevertheless, a high level of enjoyment was registered. The results of this study have confirmed the need to expand the framework for the rehabilitation of young people with cerebral palsy and to build appropriate systems of additional support in order to focus extracurricular activities on reducing the negative effects of a disability. However, this research did not include contextual and social factors that are significant in the participation of young people with cerebral palsy in leisure activities.

The first longitudinal participation study aimed to determine early predictors of leisure participation in formal and informal activities in school-aged children with cerebral palsy (Bult et al., 2013). Overall, at the child level, movement ability and social skills measured at two years of age were most predictive of leisure participation at six years of age, explaining 62% of the variance in informal activities. It is important to note that different predictors were identified for formal and informal activities. Early predictor identified at the family level was restricted family participation, while the type of day-care was determined at an environmental level. An earlier study showed that every other parent felt restricted in the family (45%) or personal activities (53%) at the time their child with cerebral palsy was 18 months old. Furthermore, from infancy (18 months) to toddlerhood (42 months), the longitudinal data showed that restrictions in family participation became more prominent as the child grew older (Rentinck et al., 2009).

A later prospective study on the stability of participation in leisure activities indicated its significant decline, which is the finding especially important for health, functioning and overall quality of life of persons with cerebral palsy (Majnemer et al., 2015). Specifically, there was a decline in diversity and frequency of recreational activities, skills-based activities and self-improvement activities from school age (6–12 years) to adolescence (12–19 years). In the same period, only social participation remained stable. Diversity of active physical activities increased modestly, yet their frequency was reduced. The decline was also noted in terms of the level to which children with cerebral palsy expressed how much they enjoyed these activities. Preferences, as a choice of a certain type of activity or how much an individual wants to participate in certain leisure activities, have remained unchanged, except for recreational activities. Although there was a decline in the enjoyment of leisure activities, preferences remained unchanged between school-age and adolescence. The authors emphasized that gender, maternal education, family income, and gross motor abilities of children with cerebral palsy were not related to changes in certain characteristics of participation in leisure activities that occurred over the years (Majnemer et al., 2015). The study included 38 children with cerebral palsy, most of whom were ambulatory (GMFCS levels I and II), i.e. had the mildest level of limitations in motor abilities.

Several studies have focused on participation in the community environment. Bedell et al. (2013) found that statistically significant differences in frequency of participation, level of involvement, and availability of environmental support. The results indicated that, in general, the participation of children with disabilities in the community environment was lower in comparison to their peers of typical development, which is consistent with earlier studies (Engel-Yeger et al., 2009). Also, more parents of children with disabilities than parents of children with typical development expressed a desire for change in the participation in community activities. The differences were most noticeable in participation in unstructured physical activities and socializing with other children, the same two types of activities for which the greatest percentage of parents of children with disabilities desired change. The environmental impact was most evident in the physical, social, and cognitive demands of the typical community-based activities, in addition to the availability and adequacy of programs and services. At the same time, environmental factors were assessed more often as barriers to active involvement.

Recently, data on 1073 children with disabilities aged 10 to 12 years confirmed greater restriction in community-based participation compared to peers without disabilities. Although participation patterns were similar, the extent to which children with and without disabilities participated in each activity differed. More precisely, children with disabilities participated with lower frequency in unstructured and organized physical activities, religious gatherings and getting together with friends (Arakelyan et al., 2020).

Reduced involvement in community-based activities, specifically outside the home and school and extracurricular activities should be considered carefully, as it is a sensitive area that requires engaging both family and social structures, to promote active engagement (Longo et al., 2013; Majnemer et al., 2015; Majnemer, Shevell, Law, Birnbaum, et al., 2008; Orlin et al., 2010). Some authors suggest that the solution is in the cooperation of parents, service providers and policymakers, believing that this is the

direction in which a better environment can be created for children and youth with cerebral palsy (Chan et al., 2005). As stated, more comprehensive health-care service for children with cerebral palsy could facilitate better integration into the community and parents have a significant role to play in this domain. However, parents of children and adolescents with cerebral palsy expressed the greatest concern for independence in self-care activities and mobility (45.8%) and all forms of treatments, therapeutic follow-ups and medical care (29.2%). Surprisingly few parents (4.3%) has given their concern and priority to social participation, including leisure, while one-fifth (21.7%) rated social participation as a low priority for their children's future. The aim of this study (Chan et al., 2005) conducted in Hong Kong was to determine the level of neurological impairment and limitations of activity and participation of children with cerebral palsy from the perspective of their parents, using specially designed questionnaires. According to the results shown, 86% of children participated in regular leisure activities, such as going to restaurants, shopping or playground. In recreational activities, such as swimming, going to the library, cultural centre or youth clubs, 54% of children with cerebral palsy participated. Special attention is given to barriers in carrying out outdoor activities. The most common problems are transport (47%), architectural barriers (28%) and discrimination (23%).

The research results are contradictory when considering the role of resource and service centres in the realization of leisure activities. Namely, rehabilitation services are important due to their association with enhancing confidence and competence in skilled tasks. In one study, it was found that children who were receiving rehabilitation services were more likely to participate in skill-based activities and enjoy active-physical activities (Majnemer, Shevell, Law, Birnbaum, et al., 2008). The role of the service is also recognized in the extent to which some of the leisure activities are realized with friends; social needs of youths with cerebral palsy should be supported, as well (Kang et al., 2010). On the other hand, no statistically significant association was confirmed between participation intensity and service delivery, that is, the extent to which services meet the needs of their users (Palisano, Chiarello, et al., 2011; Palisano, Orlin, et al., 2011). However, family structure and relationships and primary caregiver education influenced services (Palisano, Chiarello, et al., 2011). Parents are also highly satisfied with medical and rehabilitation services and believe that the medical aspects of rehabilitation play a key role in their children's future (Chan et al., 2005).

Earlier, testing a theoretically based model of determinants of participation in leisure and recreational activities of children with physical disabilities aged six to 14 years, it was found that family cohesion, unsupportive environments, and supportive relationships for the child had significant indirect effects on participation (King et al., 2006). Functional abilities, family participation in social and recreational activities, but also the child's preferences for certain formal and informal activities are listed as direct predictors. The model included personal factors related to the child's preferences, abilities, skills and self-concept, then family factors, i.e. family priority activities, support and resources, as well as environmental factors related to the absence of barriers and support provided to the child, as well as to the family. This model explained 30% of the intensity variance, i.e. frequency of participation in informal activities that did not require planning and 18%

variance of intensity, i.e. frequency of participation in formal activities organized by adults.

Lack of programs and resource centres, inadequate social support, unavailability of information, the inconsistency of social policy with social changes and the current social situation, together with generalized negative attitudes towards people with disabilities and inaccessible environment, are the most common environmental barriers (Bedell & Dumas, 2004). Participation of children with disabilities in the community is shaped by the physical and social characteristics of this environment, but also under the influence of attitudes (Chan et al., 2005; Hammal et al., 2004; King et al., 2003; Law et al., 2007; Michelsen et al., 2009; Mihaylov et al., 2007; Nedović et al., 2012).

A population study conducted in nine regions of seven European countries involved 813 parents of children with cerebral palsy and 2,939 parents of children from the general population aged seven to 13 (Michelsen et al., 2009). The aim was to investigate how the frequency of participation varied between children with cerebral palsy and the general population and to examine variations across different countries to understand better the impact of environmental factors (legislation, regulations and public attitudes) on participation in different countries. *The Frequency of Participation – FPQ* (Michelsen et al., 2009) was used to measure participation in everyday activities, which is a customized, shorter version of the *Assessment of Life Habits instrument – LIFE-H* (Fougeyrollas, 1998). The participation of children with cerebral palsy was less frequent in most, but not all, areas of everyday life. Variations in the domains were confirmed between the regions, but also in the magnitude of the differences. The results led to the conclusion that the different environments could explain variations between regions, given that certain factors (such as attending a special school) were not associated with further reductions in participation in most areas of daily life.

Continuing previous research, Colver et al. (2012) evaluated how the participation of children with cerebral palsy varied with their environment. The results confirmed that the physical, social, and attitudinal environment of children with cerebral palsy influenced their participation in everyday activities and social roles. Specifically, participation in daily activities was associated with a better physical home environment, while mobility was related to the transport and physical community environment. On the other hand, participation in social roles, in turn, was related to the attitudes of classmates and social support at home. Collectively, the environment explained between 14% and 52% of the variation in participation.

Next, the frequency of participation varied according to the level of activity limitations: gross motor (GMFCS), manual (MACS)⁵ and communication (CFCS).⁶ Specifically, in a sample of 109 children with cerebral palsy aged six to 12 years, it was confirmed that higher level of impairment of these functions was accompanied by a lower frequency of participation in various activities including participation in the community (Park & Kim, 2015). The key differences are between the levels I and V. Gross motor and

⁵ MACS = Manual Ability Classification System

⁶ CFCS = Communication Function Classification System

communication abilities, expressed through the level of activity limitation, were confirmed as predictors. Together, activity limitations explained 26.5% of the variance in participation frequency ((Park & Kim, 2015). The functioning, activity and participation of school-age children with cerebral palsy (according to ICF-CY) are depending on manual abilities (MACS), and it has been confirmed that functioning affects their activities and participation (Lee et al., 2015).

It is noteworthy that low diversity and lower intensity, i.e. frequency does not necessarily indicate that participation is restricted, especially given the importance of engaging in preferred leisure activities (Longo et al., 2013). At the same time, other research suggests registering an increasing trend in the number of people with cerebral palsy who successfully integrate into their social environment and who, in addition to moderate to severe disabilities, show independence in everyday life activities and employment. The reason for this change lies in advances in rehabilitation and rehabilitation techniques, better resource centre services, and changes in environmental factors that are now facilitating for a person with disabilities (Murphy et al., 2008).

Previous studies reported that children with disabilities tended to participate in a wide range of different activities and that the level of their enjoyment with the achieved participation was high, despite the significantly lower frequency of these activities (Imms et al., 2008; Law et al., 2006; Majnemer, Shevell, Law, Birnbaum, et al., 2008; Shikako-Thomas, Shevell, Lach, et al., 2013; Vila-Nova et al., 2020). Participation depends on individual determinants, i.e. those related to the child and environmental determinants, i.e. factors from the socio-cultural environment, but also from their interaction. In addition, according to reports, children with disabilities were more often restricted when participating in the community than at home or at school. As an explanation of this phenomenon, the literature states that environmental barriers are encountered more frequently and that a greater challenge is to anticipate and change or modify environmental features in the community than in the home or school setting (Bedell et al., 2011; Bedell & Dumas, 2004; Law et al., 1999, 2007).

Participation in daily activities is considered important for the quality of life of children with cerebral palsy. However, examining the relationship between participation in daily activities and quality of life of children with cerebral palsy of school age, Mc Manus et al. (2008) have concluded that, although restricted, participation had a limited effect on the quality of life. Low participation did not predict mental health disorders in this population, neither (Whitney et al., 2019). Nonetheless, increased impairment restricts participation in the majority of daily activities, including leisure activities (Mc Manus et al., 2008). More severe level of impairment was associated with lower participation. Individually, no differences were found in relation to the age and gender of children. Level of impairment of children was recorded according to the gross motor, fine motor and intellectual abilities. Age, gender, and level of impairment together account for 27.4% of the variance in overall participation. However, a statistically significant association between increased severity of impairment and diminished quality of life was found in only two of the ten domains examined: Physical well-being and Social support and peers. Overall participation, observed independent of age, gender and level of impairment, was related significantly to the three domains of quality of life (Physical well-

being, Social support and peers, Mood and emotions). In other words, the level of achieved participation in everyday activities has a limited effect on the quality of life. The study included 98 children with cerebral palsy aged eight to 12 years. As assessment tools, in addition to the GMFCS and BFMF scales for assessing the level of impairment, FPQ was used for measuring participation in daily activities and the KIDSCREEN-52 Quality-of-Life Measure for Children and Adolescents (Ravens-Sieberer et al., 2005) for measuring the quality of life. As explained, data were collected from parents; therefore, results show the participation and quality of life of children with cerebral palsy seen from a parental perspective.

In a qualitative study on factors that negatively or positively affect the quality of life, adolescents with cerebral palsy gave great importance to freedom in choosing activities and socializing with friends (Shikako-Thomas et al., 2009). Namely, the experienced quality of life was influenced directly by the provision of opportunities for active involvement in the preferred activities and such a perception was consistent regardless of the objectively present level of motor impairment. The authors have interviewed 12 adolescents with cerebral palsy aged 12 to 16 years and revealed internal and external factors that make a difference in their life satisfaction. The quality of life of adolescents was mostly reflected in the interaction of internal and external factors visible through the relationship between personal interests and preferences, on the one hand, and opportunities to engage in leisure and age-appropriate activities, on the other hand.

METHODOLOGICAL CONSIDERATIONS

Research aim, research questions and hypotheses

Following the problem statement and rationale, we consider it relevant to explore the specifics of the participation of children with cerebral palsy across various settings and activities. The question is how parents evaluate the participation of their children with cerebral palsy, how the presence of cerebral palsy, as multiple disabilities, leads to differences in the characteristics of participation and in which type of activities these changes are most noticeable. The answers to these questions could be helpful in many ways, for example, as guidelines in decision making, especially concerning the rehabilitation programs and services. Besides, they may also be useful when counselling on improving community participation by indicating what adjustments or modifications are needed and what resources, services and supplies should be provided.

This study aimed to examine the characteristics of community participation of children with cerebral palsy in comparison to their peers with typical development and the effect of the environment on this participation, from the perspective of parents.

The following *research questions* were posed:

- (1) Are there differences in characteristics of participation in community-based activities between the group of children with cerebral palsy and the group of children with typical development?
- (2) Are there differences in the structure of environmental factors relevant to community participation between the group of children with cerebral palsy and the group of children with typical development?
- (3) Are the characteristics of community participation and the features of the community environment related to the functional limitations of children with cerebral palsy?

The following *research hypotheses* were posed:

- (1) Characteristics of participation in community-based activities differ between the group of children with cerebral palsy and the group of children with typical development.
- (2) Structures of environmental factors relevant to community participation differ between the group of children with cerebral palsy and the group of children with typical development.
- (3) Functional limitations of children with cerebral palsy are associated with the characteristics of community participation and features of the community environment.

Method

Design, procedure and ethical considerations

This study is part of a larger research project focused on participation and family quality of life of children with cerebral palsy living in Serbia.⁷ The research project that made the empirical basis of this study was designed and conducted as a descriptive, cross-sectional, comparative, and exploratory study of two groups of children.

The convenience sampling method was used. Sixty-five health, educational and social welfare institutions, as well as national and local disability organizations and associations from 48 municipalities of Serbia, were contacted. Thirty-five (53.8% response rate) responded positively to our request for cooperation in this research project and allowed us to access their registers and select potential participants.

The general inclusion criteria were as follows: children of both genders, aged 7–18 years, residing with their families on the territory of the Republic of Serbia. The inclusion criterion for the group of children with cerebral palsy was *cerebral palsy* diagnosed by a physician, according to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10; WHO, 2004). For the group of children with typical development, exclusion criteria were as follows: a history of psychological, neurological, motor or speech and language issues that might affect children's participation, according to their parents' report.

Parents or legal caregivers of children with cerebral palsy were reached as informants mostly through disability services, regular and special schools and special school services, day-care centres for persons with disabilities, hospitals and rehabilitation centres, and several associations of persons with cerebral palsy or associations and persons with other disabilities. For the group of children with typical development, recruitment was conducted through regular schools and their databases, and by using snowball sampling from initial participants.

In the next step, 397 research invitations with the questionnaire package were distributed by regular mail. The questionnaires were accompanied by a letter with Information Sheet about the study. Information Sheets was used to describing the aims, methods and implications of the research. More precisely, parents were informed that results obtained from analysing the data in this research would contribute to a better understanding of the participation of children with cerebral palsy and the acknowledgement of the importance of their involvement and participation in activities in different environments. It was stated explicitly that participation was voluntary and free and that anyone had the right to refuse to participate and to withdraw their consent to participate, without any consequences.

⁷ This study is a result of the doctoral thesis prepared by Milena Milićević (2016).

The study was approved by the Professional Boards of The Belgrade University (No. 61206-2385/2-14) and conducted following the principles of the Declaration of Helsinki. The principle of 'data minimization' was followed and implemented, as well as selected pseudo-anonymization techniques. Direct identifiers are held separately and securely from data processed. These refer to a name, an identification number, location data, e-mail, and phone number.

Two follow up calls were made, the first two weeks after the packages were sent, and the second one month later. The assistance of the researcher was available all the time, including home visits to pick up the questionnaire and phone or Skype calls if requested.

A total of 244 questionnaires were collected (61% response rate) during the period from June 2014 to April 2015. Signed informed consents were returned with the completed questionnaires from all parents and caregivers included in this study.

Data collection and measures

After the informed signed consents were received, the data were collected from the available personal medical, educational or psychological records.

The data about the type of cerebral palsy, as diagnosed by a physician, were categorized as spastic quadriplegia, spastic diplegia, spastic hemiplegia, dyskinetic cerebral palsy, athetoid cerebral palsy, ataxic cerebral palsy or mixed cerebral palsy.

The intellectual functioning of children with cerebral palsy was categorized as normal intellectual functioning (IQ above 85), borderline intellectual functioning (IQ range, 70–84), mild intellectual disability (IQ range, 50-69), moderate intellectual disability (IQ range, 35-49), and severe intellectual disability (IQ range, 20-34). Generally, intellectual functioning was tested by the Revised Scale for Measuring Intelligence according to Wechsler principles – REVISK (Biro, 1997), which is a locally standardized approximation of WISC-III. In cases where data on IQ level was not available, the data on the category of intellectual functioning was recorded.

The main research instruments were the following:

- (1) Gross Motor Function Classification System – Expanded and Revised, GMFCS–E&R (Palisano et al., 2007),
- (2) Manual Ability Classification System – MACS (Eliasson et al., 2006),
- (3) Participation and Environment Measure for Children and Youth – PEM-CY (Coster et al., 2010), and
- (4) A demographic questionnaire.

Gross motor functioning and fine manual abilities of children with cerebral palsy were described by using GMFCS⁸ and MACS. Data on children's community participation and the environment were gathered with PEM-CY. A questionnaire concerning demographics was created for this study. It is important to note that GMFCS, MACS and PEM-CY are not part of the standard assessment and documentation of children with cerebral palsy in Serbia. Therefore, data were collected from informants.

The Gross Motor Function Classification System – Expanded and Revised (GMFCS–E&R; Palisano et al., 2007), version in Serbian (translation: Miličević & Stojanović, 2013) determines the level that best represents the child's current gross motor abilities and limitations, based on the assessment of self-initiated movements, meaningful in everyday life, with a special emphasis on sitting, transfer, and mobility. The usual performance is followed, not what is known that the child can do at its best (capability), as well as the impact of environmental (physical, social, attitudes) and personal factors (motivation, interests, preferences).

The Manual Ability Classification System (MACS; Eliasson et al., 2006) describes how the child uses its hands to handle objects in the activities of daily life. MACS is designed to evaluate the child's self-initiated ability to handle age-appropriate objects, and the need for assistance or adaptation to accomplish everyday life tasks. The assessment is based on a typical performance, without considering the functional differences between the hands, the functioning of each hand separately or explaining the causes of impairment of manual abilities. The Serbian version is used (translation: Golubović, Slavković, & Starović, 2010).

Overall, GMFCS and MACS are classification systems used worldwide as a unique way of describing and classifying the motor skills of children and young persons with cerebral palsy based on functional abilities and limitations. Both GMFCS and MACS are five-level ordinal scales, with a higher level indicating greater functional limitation. The title for each GMFCS level represented the most characteristic method of mobility for a particular age range, while MACS levels are designed to match GMFCS levels (Table 2).

Taken together, they provide useful information that completes the clinical picture of CP (Imms et al., 2010). In contemporary disability studies, GMFCS and MACS are considered the leading classifications of mobility and fine motor abilities. Numerous studies have confirmed the reliability and the overall stability of these instruments, as well as their discriminatory, constructive and predictive validity (Beckung & Hagberg, 2002; Eliasson et al., 2006; Himmelmann et al., 2006; Imms et al., 2010; Kuijper et al., 2010; Palisano et al., 2000, 2006, 2008; Wood & Rosenbaum, 2007).

⁸ The abbreviation GMFCS is used as the common in the literature, with the implied referring to GMFCS–E&R.

Table 2. *The criteria of classification of motor abilities according to GMFCS and MACS⁹*

Level	GMFCS	MACS
I	Walks without limitations; limitations in more advanced gross motor skills.	Handles objects easily and successfully.
II	Walks with limitations; limitations when walking outdoors and in the community.	Handles most objects but with somewhat reduced quality and/or speed of achievement.
III	Walks indoors using a hand-held mobility device; use wheeled mobility outdoors and in the community	Handles objects with difficulty; needs help to prepare and/or modify activities.
IV	Self-mobility with limitations; may use a manual wheelchair or powered mobility	Handles a limited selection of easily managed objects in adapted situations.
V	Severe limitations in head and trunk control; self-mobility only by a powered wheelchair; usually transported in a manual wheelchair	Does not handle objects and has severely limited ability to perform even simple actions.

Note. GMFCS = Gross Motor Function Classification System, expanded and revised version (Palisano et al., 2007); MACS = Manual Ability Classification System (Eliasson et al., 2006).

For this study, the community section of the *Participation and Environment Measure for Children and Youth* (PEM-CY; Coster et al., 2010), Serbian version (translation: Milićević, 2013), was used to gather data. It is a parent/caregiver-report instrument that was initially designed and validated for use in population-based research on the participation of children aged 5–17 years with and without disabilities (Khetani et al., 2014). Detailed information about the conceptual basis, development, and psychometric properties of the PEM-CY have been described earlier (Bedell et al., 2011, 2013; Coster et al., 2011, 2012; Khetani et al., 2014).

The PEM-CY provides an assessment of:

- (a) Children’s participation across a broad range of activities in a specific setting (i.e., home, school, community),*
- (b) Multiple dimensions of a child’s participation (frequency, involvement, change desired),*
- (c) A broad range of environmental factors, that is, barriers and supports in terms of their perceived impact on the child’s participation, and*
- (d) Relevant content and response options for parents of youth with and without diverse disabling conditions.*

⁹ Adapted from: Carnahan et al., 2007, p. 51.

The PEM-CY demonstrated acceptable to good reliability, comparable to the values reported by the authors (Coster et al., 2011). An internal consistency coefficient for 'frequency' was 0.78 and 0.70 for 'involvement' across the community setting. Similarly, Cronbach's alpha for the 'change desired' was 0.84, and for the 'total environmental supportiveness' 0.90.

With written consent and approval of the first author (Wendy Coster) and the PEM-CY Coordinator (Rachel Teplicky, personal communication, July 2, 2013), the instrument was completely translated from English into Serbian. The back-translation method was used. After some minor adjustments, these two versions were compared and approved by the authorized person from the CanChild research group. When a positive review was received, the PEM-CY in Serbian was finalized.

The following cultural adaptations were made:

- (1) *washing the dishes* was added in 'Household chores',
- (2) *packing snacks* replaced *packing lunch* in 'School preparation',
- (3) *studying* replaced *school projects* in 'Homework',
- (4) *hockey* and *martial arts* were excluded, and *fencing* included in the 'Organized physical activities',
- (5) *skateboarding* was excluded from the 'Unstructured physical activities',
- (6) *brownies/girl guides* was excluded from 'Organizations, groups, clubs, and volunteer or leadership activities',
- (7) *paper route* was excluded from 'Working for pay', and
- (8) *camp* was changed to *trips* in 'Overnight visits or trips'.

The parents were asked to rate how frequently their child participated in each of ten community-based activity types over the past four months (on an 8-point scale, ranging from 0 = never to 7 = daily). Secondly, they were asked to rate how involved the child was while participating (on a 5-point scale, ranging from 1 = minimally involved to 5 = very involved) and whether they would like to see the child's participation change ("no" or "yes"). If "yes", the parents were asked to clarify the type(s) of change desired among five options: a) do more often, b) do less often, c) be more involved, d) be less involved, and e) be involved in a broader variety of activities.

Next, for each setting, the parents were asked whether certain features of the environment help or make it harder for their child to participate in activities in the community (response options: Usually makes harder = 1, Sometimes helps, Sometimes makes harder = 2, Usually helps AND Not an issue = 3). Finally, the parents were asked about adequacy/availability of resources to support their child's participation in the community (response options: Usually no = 1, Sometimes yes, Sometimes no = 2, Usually yes AND not needed = 3). There are 16 items or environmental features in this part of the PEM-CY community section.

Variables – Operationalization and indicators

Nine summary scores related to community participation and community environment calculated from the PEM-CY are described in Table 3.

Table 3. *Descriptions of PEM-CY community summary scores*

Variable	Full description and scoring
1. Participates ever, %	An indicator of the range or diversity of activities in which children take part. The number of items responded 1 (once in last four months) to 7 (daily) divided by the total number of items rated and then multiplied by 100. Higher percentages indicate that children participate in more activities (range = 0–100%).
2. Participation frequency	Mean of frequency ratings across all 10 activity types except those to which parent responded 0 (never) for frequency. Higher scores indicate greater frequency across activities (range = 1–7).
3. Level of involvement	Mean of all involvement ratings except those to which parent responded 0 (never) for frequency. Higher scores indicate greater involvement across activities (range = 1–5).
4. Desire for change, %	An indirect indicator of overall parental satisfaction with the child’s current participation. The number of “yes” responses divided by the total number of items rated and then multiplied by 100. Higher percentages indicate a greater number of activities that parents desire change in their child’s participation (range = 0–100%).
5. Number of barriers	The average count of environmental items rated as “usually makes harder” or “usually no”. Higher scores indicate a greater number of supports within a community.
6. Number of supports	The average count of environmental rated as “usually helps” or “usually, yes”. Higher scores indicate a greater number of barriers within a community.
7. Environmental helpfulness, %	An indicator of the parent’s perception of how helpful the environment is in supporting the child’s participation. Sum of ratings on environmental features divided by the maximum possible score (the highest value for each item is 3 x number of items) and then multiplied by 100. Higher percentages indicate that the environment is more helpful.
8. Environmental resources, %	An indicator of the parent’s perception of the availability of environmental resources. Sum of ratings on environmental resources divided by the maximum possible score (the highest value for each item is 3 x number of items) and then multiplied by 100. Higher percentages indicate that the resources are more available.
9. Total environmental supportiveness, %	An overall indicator of the parent’s perception of how the environment supports the child’s participation in the community. Sum of ratings of environmental features and resources divided by the maximum possible score (the highest value for each item is 3 x 10 items = 30) and then multiplied by 100. Higher percentages indicate that the environment provides more support.

In this study, the operationalization of community participation given by Kang (2010) was used. The community participation was operationally defined as “a child’s involvement in activities that are performed outside the home environments, including the neighbourhood, extracurricular activities at school environment, within and beyond the community where the child lives” (p. 29).

Characteristics of participation include three variables, namely *the diversity of activities* in the community environment, i.e. the representation of those activities in which the children have participated in relation to those in which they have never participated, then the *frequency* of involvement in activities of a certain type, and *the level of involvement* in the given activities. The level of parent’s satisfaction with the achieved participation is determined through the percentage of community activities in which a parent wants to see change. Additionally, the type of change desired was examined.

The structure of environmental factors includes the representation of facilitators or supports and the representation of barriers as environmental factors specific to the community environment. It also includes an overall indicator of the parent’s perception of how the environment supports the child’s participation, an indicator of the parent’s perception of how helpful the environment is and an indicator of the parent’s perception of the availability of environmental resources.

Data analysis

Descriptive statistics were used to summarize demographic characteristics and outcomes. Radar plots were used to display patterns in item-level data.

Chi-squared tests were conducted for categorical responses, with Fisher Continuity Correction if needed (i.e. gender, age, education). As a measure of association, ϕ coefficient and Cramer’s V were reported and interpreted as small (0.10–0.29), moderate (0.30–0.49) or large (0.50–1.00) effect sizes (Pallant, 2007).

Analyses of covariance (ANCOVA) was used to compare differences in the PEM-CY community participation and environment summary scores between the group of children with cerebral palsy and the group of children with typical development. The family income category was entered as a covariate because of group difference on this variable (Table 4).

Age and education of parents were not included in the analyses because F-tests indicated no significant interaction effects between these variables and group across all participation scores. That is, the differences in participation and overall environmental supportiveness between two groups were not dependent on parents’ age or education level (Table S1, S4, S5 and S8, Supplementary data). Partial Eta squares (η^2_p) were used to examine effect sizes, and values were interpreted as small (0.01–0.05), moderate (0.06–0.13) or large (≥ 0.14) effect sizes (Pallant, 2007).

The relationship between characteristics of community participation and environmental features and functional limitations of children with cerebral palsy was tested using the

Spearman's rank correlation. The coefficients of Spearman's rank correlation were interpreted as small (0.10–0.29), moderate (0.30–0.49) or strong (0.50–1.00).

The significance level was set at $p < 0.05$. However, due to multiple comparisons, Bonferroni corrections were made by dividing 0.05 by the number of comparison tests conducted for each set of analyses.

Study sample

Child, family and respondent characteristics are given in Table 4.

Table 4. *Child, family and respondent characteristics*

Variable	CP group	TD group	p (ϕ or V) ^a
Child gender			
Male	61 (55.5)	61 (48.8)	0.375 (0.07)
Female	49 (44.5)	64 (51.2)	
Child age (years)	$M = 12.67, SD = 3.41$	$M = 12.07, SD = 3.15$	
7–12	48 (43.6)	66 (52.8)	0.203 (-0.09)
13–18	62 (56.4)	59 (47.2)	
Informant relation to child			
Mother	87 (79.1)	104 (83.2)	0.188 (0.12)
Father	18 (16.4)	20 (16.0)	
Guardian	5 (4.5)	1 (0.8)	
Informant age (years)	$M = 41.28, SD = 7.16$	$M = 40.38, SD = 4.87$	
25–34	17 (15.4)	9 (7.2)	0.012 (0.19)
35–44	64 (58.2)	95 (76.0)	
44+	29 (26.4)	21 (16.8)	
Informant education			
Primary school	9 (8.6)	1 (0.8)	< 0.001 (0.31)
High school	69 (65.7)	57 (46.7)	
College or university	27 (25.7)	64 (52.5)	
Family type			
Single-parent	22 (20.0)	21 (16.8)	0.643 (-0.04)
Two-parent	88 (80.0)	104 (83.2)	
Family income per month (EUR) ^b			
< 165	26 (23.6)	2 (1.6)	< 0.001 (0.53)
165–410	52 (47.3)	23 (18.4)	
410–820	20 (18.2)	68 (54.4)	
> 820	12 (10.9)	32 (25.6)	
Type of community			
Urban	63 (57.3)	89 (71.2)	0.052 (0.16)
Suburban/Small town	21 (19.1)	20 (16.0)	
Rural	26 (23.6)	16 (12.8)	

Note. CP group = Group of children with cerebral palsy ($n = 110$); TD group = Group of children with typical development ($n = 125$). Values are n (%) or as otherwise indicated.

^a p is based on chi-square analysis.

^b Converted from RSD 2014-11-24.

The final sample included 110 children with cerebral palsy (55% males; mean age 12y 8mo [SD 3y 5mo]) and 125 children with typical development (49% males; mean age 12y 1mo [SD 3y 2mo]). There were no statistically significant differences between groups in relation to gender ($\chi^2(1) = 0.79, p > 0.05, \phi = 0.07$) and age of children ($\chi^2(2) = 1.62, p > 0.05, \phi = -0.09$).

Most informants were mothers, aged 35–44 years, with high levels of education (high school or college/university). Most families had two parents and resided in urban areas.

Moreover, there were differences between groups in relation to informants age ($\chi^2(2) = 8.86, p < 0.05, V = 0.19$), informants education ($\chi^2(2) = 21.43, p < 0.001, V = 0.31$) and family income per month ($\chi^2(3) = 66.37, p < 0.001, V = 0.53$). These three family characteristics were subsequently included in the statistical analysis as potentially confounding variables.

Additional characteristics of the group of children with cerebral palsy are summarized in Table 5. The most common was a spastic type of cerebral palsy diagnosed in 70% of children, accompanied by cognitive (67.3%) and visual impairments (33.6%), as well as epilepsy (25.4%).

Table 5. *Characteristics of group of children with cerebral palsy (n = 110)*

Variable	n (%)
GMFCS	
I / II / III	15 (13.6) / 29 (26.4) / 22 (20.0)
IV / V	29 (26.4) / 15 (13.6)
MACS	
I / II / III	12 (10.9) / 35 (31.8) / 19 (17.3)
IV / V	28 (25.5) / 16 (14.5)
Type of cerebral palsy	
Spastic quadriplegia	37 (33.6)
Spastic diplegia	25 (22.8)
Spastic hemiplegia	15 (13.6)
Dyskinetic / Athetoid	12 (10.9)
Ataxic	11 (10.0)
Mixed	10 (9.1)
Sensory impairments	
Visual	37 (33.6)
Hearing	4 (3.6)
Combined	9 (8.2)
Intellectual functioning	
Normal / Borderline	26 (23.6) / 10 (9.1)
Mild intellectual disability	31 (28.2)
Moderate / Severe intellectual disability	31 (28.2) / 12 (10.9)
Epilepsy	28 (25.4)
Health problems	23 (20.9)

Note. GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System.

Mild gross motor limitations (GMFCS I–II) are predominant in participants with spastic hemiplegia (66.7%) and ataxia (54.6%). Severe gross motor limitations (GMFCS IV–V) are more frequent in participants with spastic quadriplegia (67.5%) and dyskinetic and athetoid cerebral palsy (75.0%) than in other clinical forms (Figure 2). These frequencies were significantly different, $\chi^2(20) = 57.53, p < 0.001, V = 0.36$.

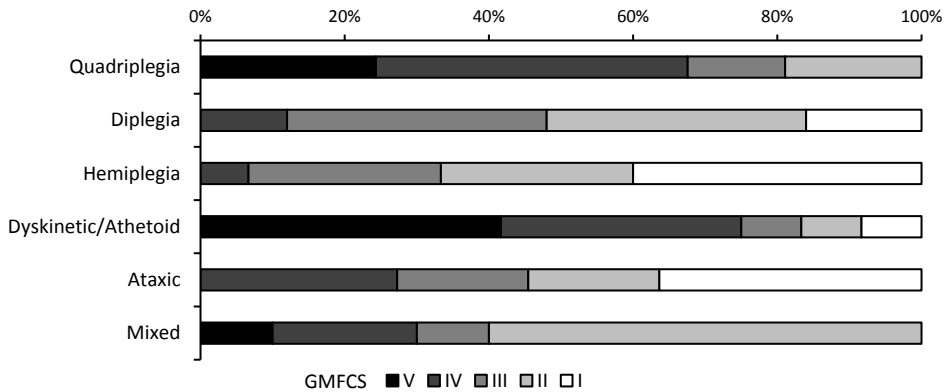


Figure 2. Distribution of gross motor function (GMFCS) in relation to the type of cerebral palsy

Mild levels of limitations in fine motor abilities (MACS I–II) are predominant in participants with spastic hemiplegia (80.0%), diplegia (68%) and dyskinetic and athetoid (66.6%). Severe limitations in fine motor abilities (MACS IV–V) are more frequent in participants with spastic quadriplegia (45.9%) and ataxic cerebral palsy (54.5%; Figure 3). However, there was no statistical significance of this difference between frequencies, $\chi^2(20) = 24.15, p = 0.236, V = 0.23$.

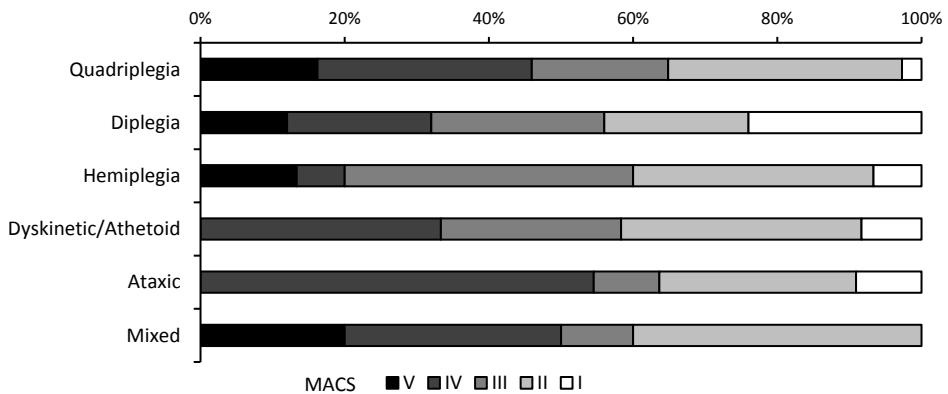


Figure 3. Distribution of gross motor function (MACS) in relation to the type of cerebral palsy

RESULTS

Community participation

Table 6 presents the descriptive statistics for PEM-CY community participation summary scores and the differences between the group of children with cerebral palsy and the group of children with typical development with adjusting for family income category. Statistically significant group differences were observed for all of the PEM-CY community participation summary scores ($p < 0.001$).

Unadjusted means of the PEM-CY community participation summary scores were very similar to ANCOVA adjusted means in both groups, so unadjusted means are presented with their corresponding SDs (Table 6). Differences between adjusted and unadjusted means were 1.68% and -1.48% for “participates ever”, 0.00 and 0.01 for “frequency”, 0.04 and -0.03 for “involvement”, and -0.98% and 0.86% for “desire for change”, in each group, respectively (Table S1, Supplementary data).

On average, children with cerebral palsy participated in 50.4% (95% CI: 46.5–54.2) of activities in the community, whereas children with typical development were involved in 74.6% (95% CI: 71.9–77.2). In other words, of the ten types of activity offered in a community setting, children with cerebral palsy participated in five activities, with a maximum of nine. Children with typical development participated in an average of 7.5 activities, with a minimum of two (Table 6).

Table 6. *PEM-CY community participation summary scores: descriptive statistics and group differences*

Community participation summary scores	Group	Min–Max	M (SD)	95% CI	ANCOVA	
				LL–UL	F (df1, df2)	η^2_p
Participates ever, %	CP	0.00–90.00	50.36 (20.36)	46.52–54.21	65.927 (1, 232)**	0.22
	TD	20.00–100.00	74.56 (15.11)	71.89–77.23		
Participation frequency	CP	1.00–6.50	4.20 (1.07)	3.99–4.40	22.228 (1, 228)**	0.09
	TD	1.50–6.40	4.83 (0.76)	4.70–4.97		
Level of involvement	CP	1.00–5.00	3.16 (1.07)	2.95–3.36	134.399 (1, 228)**	0.37
	TD	2.67–5.00	4.63 (0.53)	4.54–4.73		
Desire for change, %	CP	0.00–100.00	72.55 (23.12)	68.18–76.92	85.128 (1, 232)**	0.27
	TD	0.00–100.00	35.84 (27.57)	30.96–40.72		

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; CI = confidence interval; LL = lower limit; UL = upper limit; η^2_p = partial eta squares (effect sizes) are rounded to two decimal points and interpreted as small = 0.01–0.05, moderate = 0.06–0.13 or large ≥ 0.14 . Bonferroni adjustment of the significance level was set at $p < 0.01$.

** $p < 0.001$ for the total model based on analysis of covariance (ANCOVA) adjusting for family income category.

The difference in the distribution of the number of activities in which the children from both groups participated is presented in Figure 4. Majority of children with cerebral palsy (59.1%) were involved in four to six activities, while more than two-thirds of the group of children with typical development (72.8%) participated in seven to nine types of activities.

It can be concluded that children with cerebral palsy participated in significantly fewer community-based activities ($p < 0.001$). According to the effect size, the magnitude of this difference is large ($\eta^2_p = 0.22$; Table 6). Expressed as a percentage, 22 per cent of the variance in the number of activities in the community in which the children participated can be explained by the independent (group) variable.

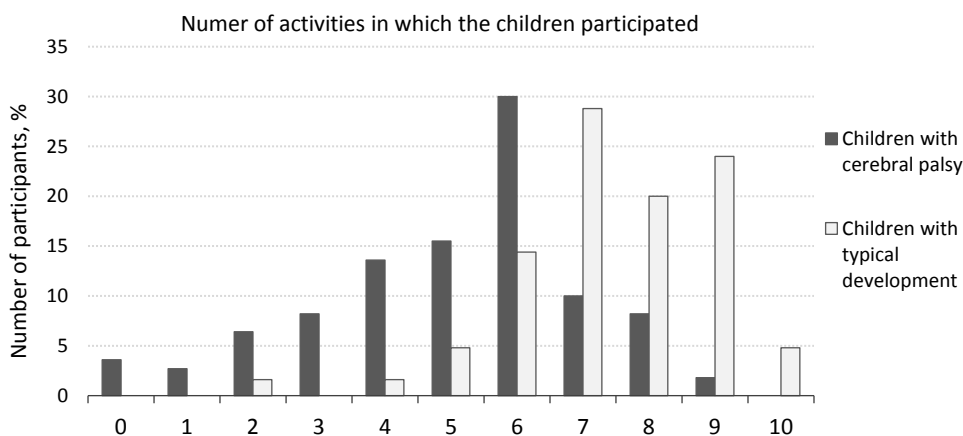


Figure 4. Number of community-based activities in which the children participated

Next, it was examined how often the children were participating in all the activities, within a community setting (Table 6). When taking into consideration only those activity types in which they had been involved, the average frequency was a few times a month in the group of children with cerebral palsy ($M = 4.2$, 95% CI: 4.00–4.4), and approximately once a week in the group of children with typical development ($M = 4.8$, 95% CI: 4.7–5.0).

When it comes to the frequency of community participation, the statistical significance is confirmed ($p < 0.001$). The magnitude of the difference between the group means was moderate ($\eta^2_p = 0.09$; Table 6). Only nine per cent of the variance in frequency of community participation can be explained by the independent (group) variable.

The distribution of average frequency is given in Figure 5. In general, the highest percentage of children with cerebral palsy (31.8%) participated a few times a month, whereas their typically developed peers mostly participated once a week (51.2%).

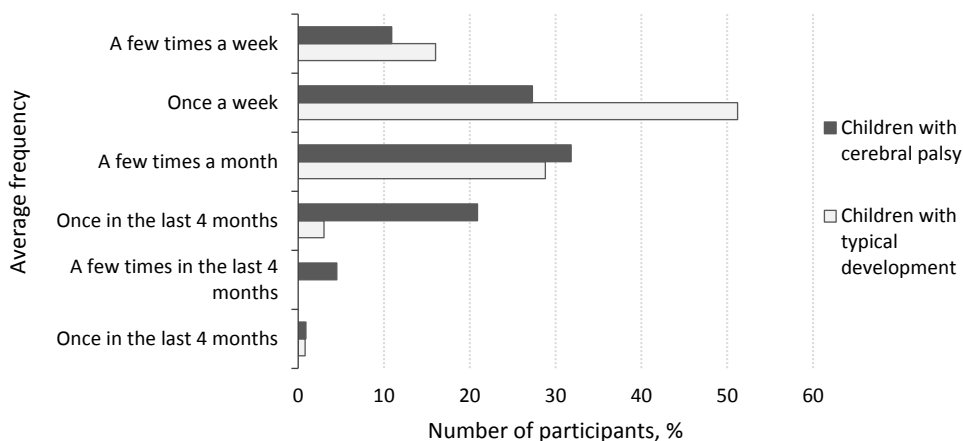


Figure 5. Frequency of community participation

The involvement in community-based activities was lower in the group of children with cerebral palsy ($M = 3.2$, 95% CI: 3.0–3.4) in comparison to how engaged the children with typical development were ($M = 4.6$, 95% CI: 4.5–4.7; Table 6). According to the distribution of the average involvement level, 30.9% of children with cerebral palsy were “somewhat involved”, and 72.0% of their typically developed peers were “very involved” (Figure 6).

Overall, children with cerebral palsy had lower levels of involvement compared to children with typical development ($p < 0.001$). Given the eta squared value of 0.37 (Table 6), it can be concluded that there is a large effect and that 37 per cent of the variance in the level of involvement in community activities can be explained by the independent (group) variable.

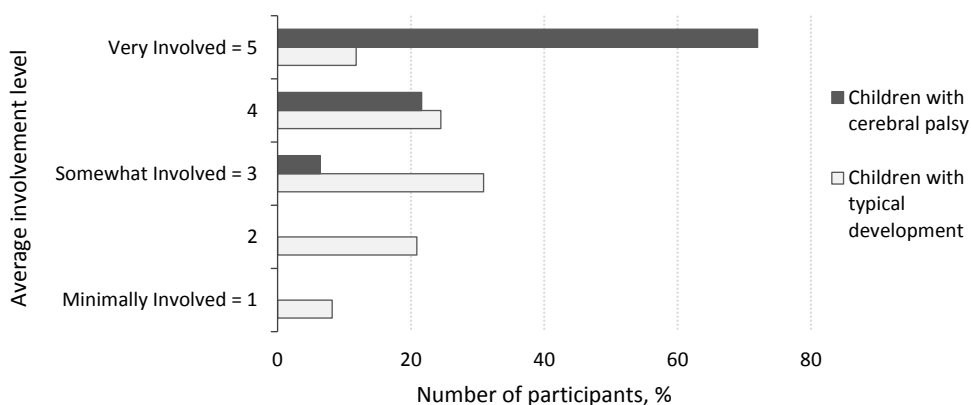


Figure 6. The level of involvement in community activities

Parents of children with cerebral palsy expressed a desire for change in more than seven of the ten activities examined ($M = 72.5\%$, 95% CI: 68.2–76.9). As presented, that same result ranged between three and four activities in the control group ($M = 35.8$, 95% CI: 31.0–40.7; Table 6).

The highest percentage of parents of children with cerebral palsy (23.6%) indicated that they wanted to see a change in all ten types of activities. Contrary to that, the highest percentage of parents of children with typical development (17.6%) reported no desire for change (Figure 7).

It can be concluded that more parents of children with cerebral palsy confirmed that they would like to see their child’s community participation change in more community-based activities than parents of children with typical development did ($p < 0.001$; Table 6). The eta squared statistic (0.27) indicated a large effect size.

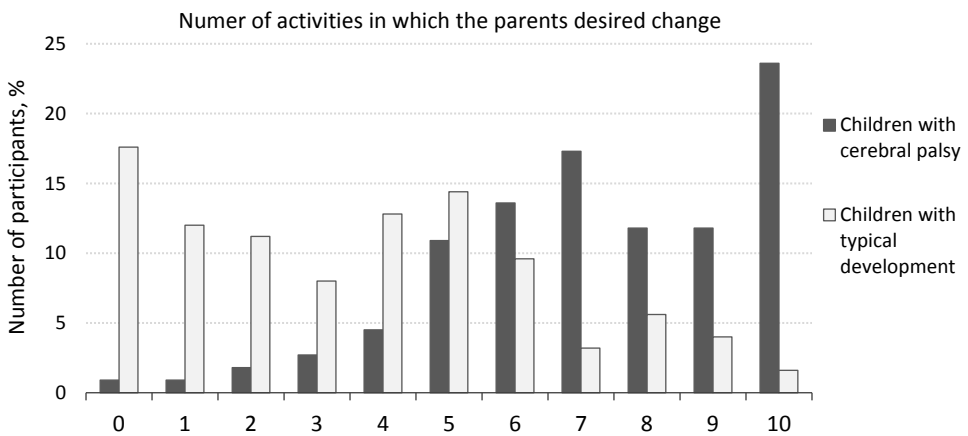


Figure 7. Number of community-based activities in which the parents expressed a desire for change

The average percentage of activities in which parents wanted to see change is an indirect indicator of their overall satisfaction with the child’s current participation. This summary score does not tell the type of change they wanted to see. To gain a better insight into this characteristic of community participation, the distribution of each type of change desired (frequency, involvement, and/or variety) is presented in Figure 8.

In the group of children with cerebral palsy, the most frequently reported types of change were related to greater frequency, involvement and variety across community-based activities (on average in 4.0, 2.0, and 2.6 activities, respectively). In addition to no change desired, parents of children with typical development highlighted the greater frequency (on average in 6.4 and 2.3 activities, respectively; Figure 8).

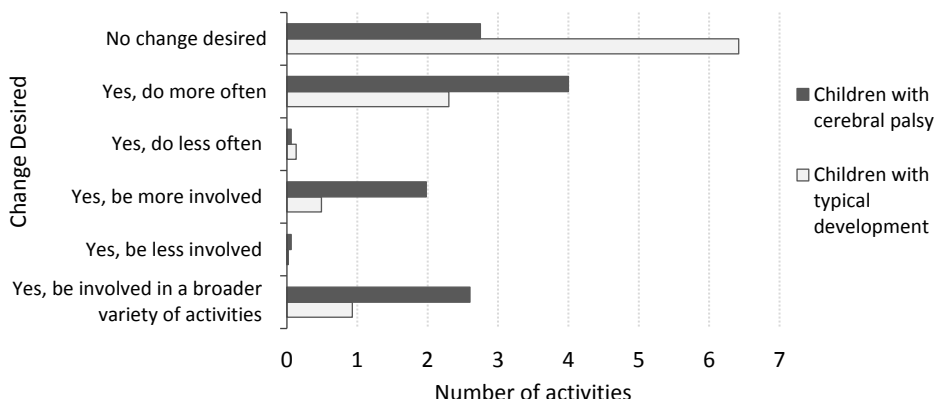


Figure 8. Type of change desired in community-based activities

Participation in individual community-based activities

Between the two groups, the participation characteristics were compared at the item level. Diversity, frequency, involvement, and the change desired are given in relation to individual types of community-based activities (Figures 9 to 12).

Participates ever, %

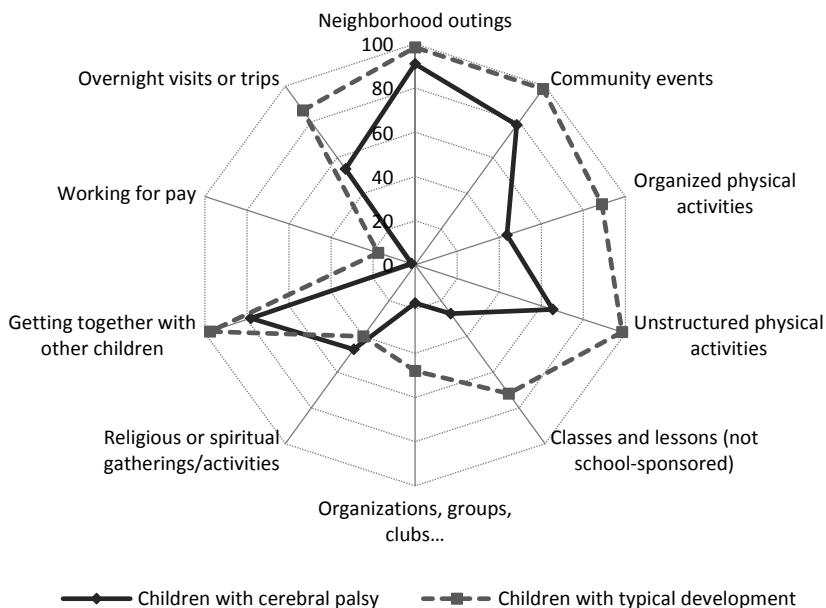


Figure 9. Diversity of participation in relation to the type of community-based activities

The percentage of children with cerebral palsy who participated in a specific type of community-based activity ranged from 1.8% (working for pay) to 90.9% (neighbourhood outings). In the group of children with typical development, the range was from 17.6% (working for pay) to a maximum of 98.4% (noted in three of ten community activity types: neighbourhood outings, community events, unstructured physical activities; Figure 9).

As shown in Figure 9, group differences are particularly evident in organized physical activities (43.6% versus 88.8%), classes and lessons not school-sponsored (27.3% versus 72.0%), as well as in unstructured physical activities (65.5% versus 98.4%). Additionally, a difference of 30% or more was found for overnight visits or trips (53.6% versus 86.4%) and volunteer or leadership activities that included activities within organizations, groups, and clubs (17.3% versus 48.0%).

Except for neighbourhood outings and religious or spiritual gatherings and activities, statistically significant differences in participation diversity were obtained in all activity types ($p < 0.001$, all). According to the effect size (ϕ), the magnitudes of these differences are moderate, ranging from 0.30 in getting together with other children to 0.48 in organized physical activities (Table S2, Supplementary data).

The only activity type in which children with typical development participated in a lower percentage were those within the domain of religious or spiritual gatherings and activities (40.0% versus 47.3%), although without the statistical significance of the group difference ($p = 0.322$, $\phi = -0.07$). Moreover, no statistical significance was found in the domain of neighbourhood outings due to Bonferroni adjustment of the significance level ($p = 0.021$, $\phi = 0.17$; Table S2, Supplementary data).

Figure 10 presents the frequency of participation in relation to the type of community-based activities. After excluding activities in which they never participated, children with cerebral palsy were involved in the specific activities from a few times in the last four months (overnight visits or trips) to once a week (neighbourhood outings). Similarly, children with typical development were participating at least a few times in the last four months (overnight visits or trips) and a few times a week at most (unstructured physical activities).

The mean participation frequency scores across items ranged from 2.0 (overnight visits or trips) to 5.4 (neighbourhood outings) for children with cerebral palsy. In the group of children with typical development, the mean participation frequency scores ranged from 2.2 (overnight visits or trips) to 6.0 (unstructured physical activities; Figure 10).

Average frequency

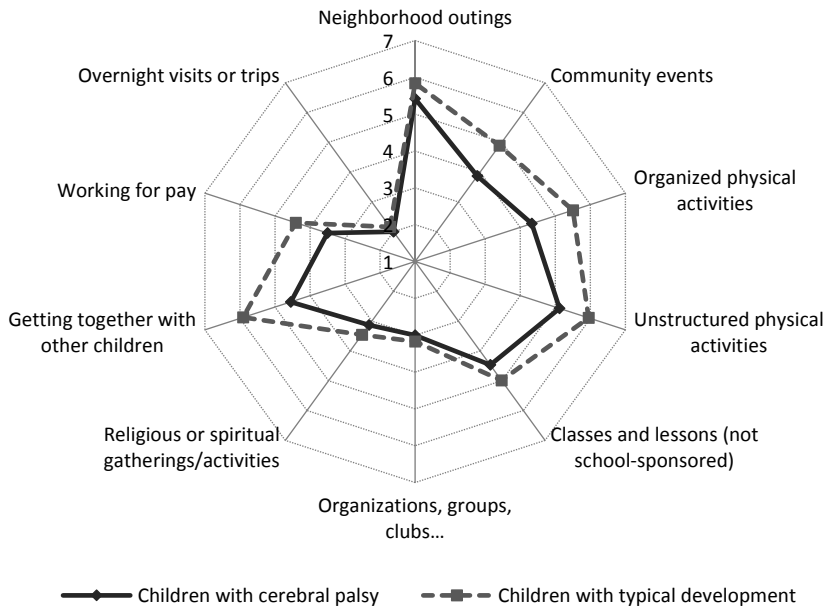


Figure 10. Frequency of participation in relation to the type of community-based activities

In all ten types of activities, children with typical development participated more frequently (Figure 10). However, there were no statistically significant differences in the average frequency in the following activity types: neighbourhood outings; classes and lessons (not school-sponsored); organizations, groups, clubs, volunteer or leadership activities; religious or spiritual gatherings and activities, and overnight visits or trips (Table S3, Supplementary data). When it comes to working for pay (e.g. babysitting, working in a store, doing chores or running errands for pay), no comparisons were conducted due to a small number of children who did participate in this activity type. Unadjusted means of participation frequency scores across items were very similar to ANCOVA adjusted means in both groups, so unadjusted means are presented (Table S4, Supplementary data).

Statistically significant differences in frequency were noted in community events ($p < 0.001$); organized physical activities ($p < 0.005$); unstructured physical activities ($p < 0.005$), and getting together with other children ($p < 0.001$). Effect sizes (η^2_p) were mostly moderate, ranging from 0.06 for unstructured physical activities to 0.09 for community events, with the largest calculated for getting together with other children (0.15; Table S4, Supplementary data).

Average level of involvement

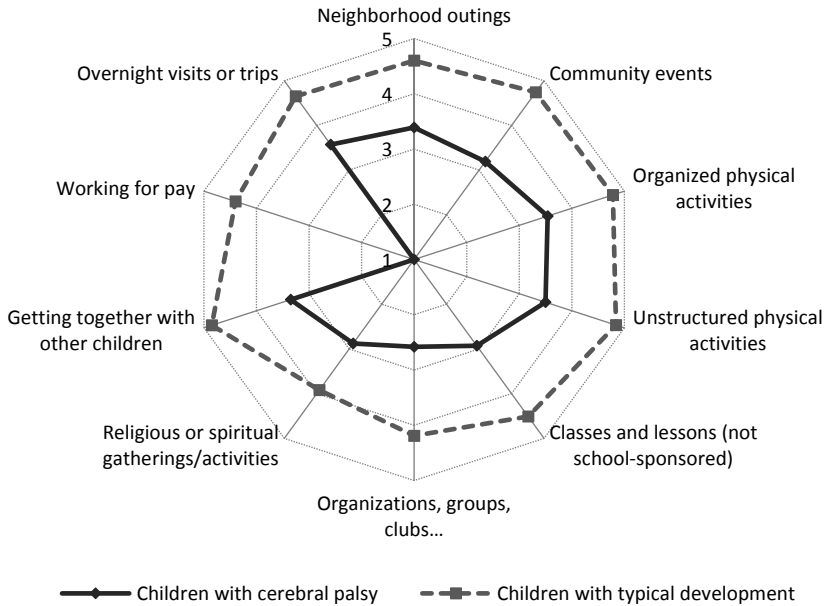


Figure 11. The level of involvement in relation to the type of community-based activities

Figure 11 illustrates similar patterns for children with cerebral palsy and children with typical development regarding the level of involvement in community activities. Mean levels of involvement across items ranged from 1.0 (working for pay) and 2.6 (organizations, groups, clubs, volunteer or leadership activities) to 3.5 (organized physical activities) in the group of children with cerebral palsy. In the group of children with typical development, mean levels of involvement ranged from 3.9 (religious or spiritual gatherings and activities) to 4.9 (getting together with other children). Unadjusted means of involvement level across items were very similar to ANCOVA adjusted means in both groups, so unadjusted means are given for descriptive purposes (Figure 11 and Table S5, Supplementary data).

Across all ten types of community-based activities, involvement ratings were lower for children with cerebral palsy ($p < 0.001$, except for religious or spiritual gatherings and activities at $p < 0.005$). Effect sizes (η^2_p) were mostly large, except for religious or spiritual gatherings and activities and overnight visits or trips with a moderate effect size (Table S6, Supplementary data). The largest effect was calculated for the difference in the level of involvement in community events (0.32).

What changes would parents want to see?

For both groups, the lowest percentage of parents who desired change in their child’s community participation was reported for religious or spiritual gatherings and activities and for working for pay (Figure 12). Overall, more parents of children with cerebral palsy desired change across all items compared with parents of children with typical development (Table S7, Supplementary data). In the group of children with cerebral palsy, that percentage ranged from 46.4% (working for pay) to 85.5% (organized physical activities). In the control group, the results ranged from 16.8% (religious or spiritual gatherings and activities) to 50.4% (classes and lessons, and organizations, groups, clubs).

Change desired, %

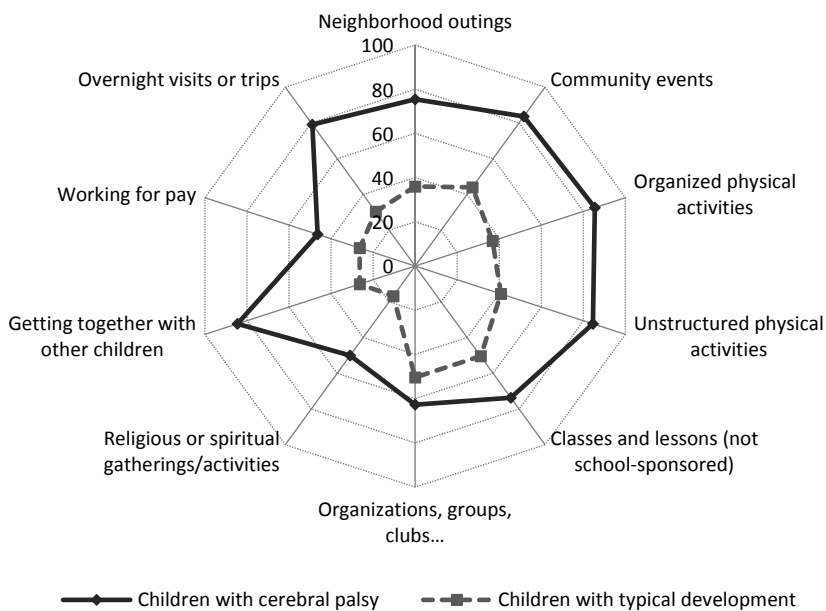


Figure 12. Percentage of parents who desired change in community participation in relation to the type of activities

A difference of 30% or more was found in seven of the ten activities included, with the largest in the following: getting together with other children (84.5% versus 26.4%), overnight visits or trips (79.1% versus 30.4%), organized physical activities (85.5% versus 36.8%), and unstructured physical activities (84.5% versus 40.8%; Figure 12).

Statistically, significant differences were obtained in nine activity types ($p < 0.001$, except for working for pay at $p < 0.005$). Effect sizes (ϕ) were mostly moderate (-0.35 to -0.49), except for classes and lessons (-0.24), and working for pay (-0.21) with a small effect size (Table S6, Supplementary data). The largest was calculated for the difference in the percentage of parents who desired change in their child’s socializing (-0.58). No

significant difference was obtained for organizations, groups, clubs, volunteer or leadership activities ($p = 0.077$, $\phi = -0.12$).

Next, more details and an examination of the group differences related to the type of change desired in each community-based activity are given (Figures 13 to 22).

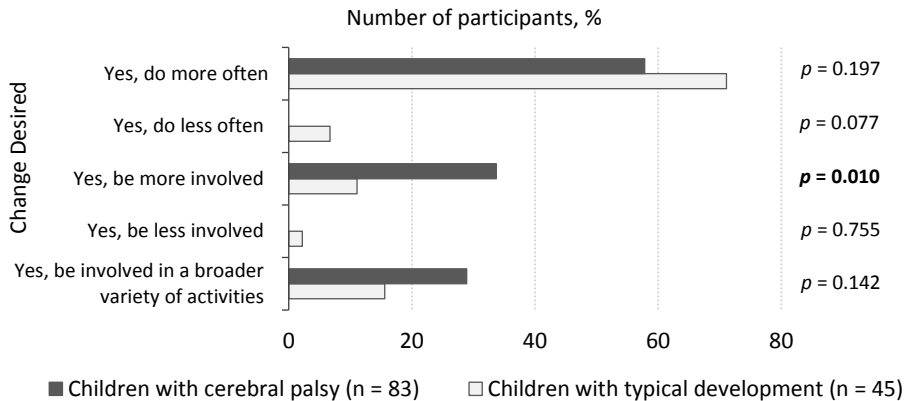


Figure 13. Neighbourhood outings: type of change desired

In general, two groups did not differ significantly in neighbourhood outings regarding the type of desired change expressed by parents (Figure 13). The highest percentage of parents from both groups would like to see their child participate more frequently in this activity (57.8% and 71.1%).

The only type of desired change that had reached the significance level with Bonferroni adjustment was related to greater involvement. While 28 (33.7%) parents of children with cerebral palsy expressed a desire for greater involvement of their children in neighbourhood outings, only five (11.1%) parents of children with typical development confirmed the same. These frequencies were significantly different, $\chi^2(1, N = 128) = 6.67$, $p = 0.010$, yet with a small effect size ($\phi = -0.25$; Figure 13).

Similarly, the highest percentage of parents from both groups expressed a desire for more frequent participation of their children in various community events, such as attending a play, concert, sports game or parade (62.0% and 81.8%; Figure 14). However, the only type of desired change that had reached the significance level with Bonferroni adjustment was related to greater involvement in this type of community-based activity. Twenty-eight (30.4%) parents expressed a desire for greater involvement of their children with cerebral palsy in various community events, as opposed to five (9.1%) parents of children with typical development. These frequencies were significantly different, $\chi^2(1, N = 147) = 7.82$, $p = 0.005$, with a small effect size ($\phi = -0.25$).

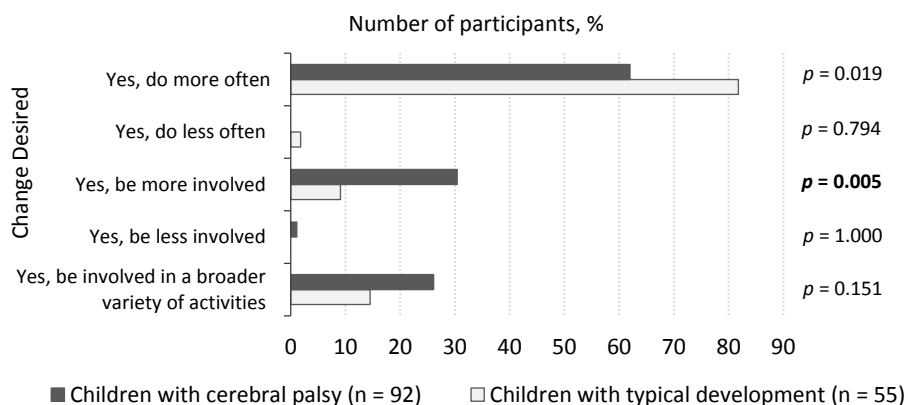


Figure 14. Community events: type of change desired

According to the results obtained, the highest percentage of parents from both groups would like to see their child participate more frequently in organized physical activities (67.4% and 58.5%). However, two groups did not differ significantly in organized physical activities except for greater involvement (Figure 15).

More parents expressed a desire for greater involvement of their child in this type of community-based activity in the group of children with cerebral palsy than in the group of children with typical development (25.5% versus 4.3%). These percentages were significantly different, $\chi^2(1, N = 140) = 7.82, p = 0.005$, with a small effect size ($\phi = -0.26$; Figure 15).

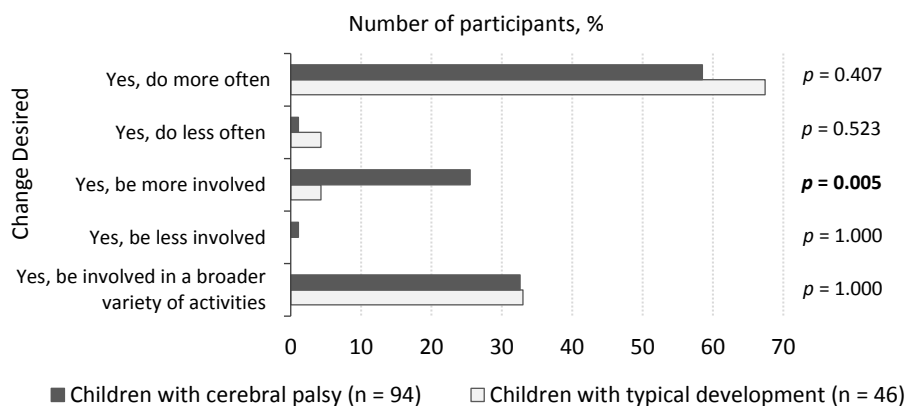


Figure 15. Organized physical activities: type of change desired

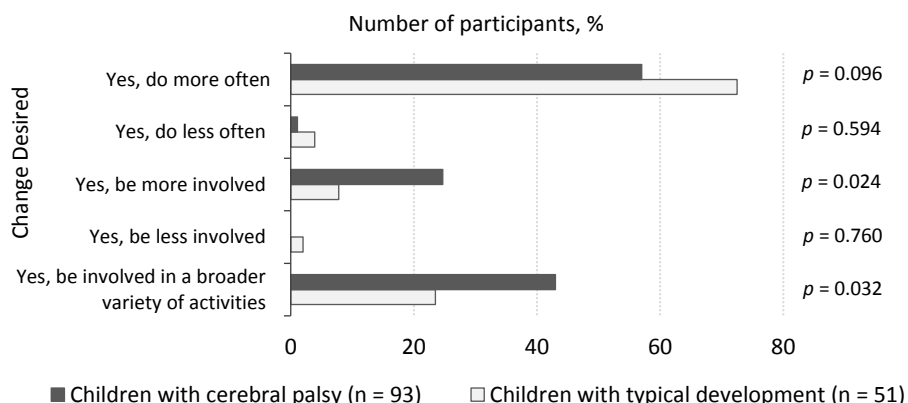


Figure 16. Unstructured physical activities: type of change desired

When it comes to unstructured physical activities, two groups did not differ significantly in relation to the type of desired change expressed by parents (Figure 16). The highest percentage of parents from both groups would like to see their child participate more frequently in this type of community-based activity (57.0% and 72.5%).

In descriptive terms, more parents of children with cerebral palsy expressed a desire for greater involvement than parents of children with typical development did (24.7% versus 7.8%, $p = 0.024$, $\phi = -0.21$). A similar trend was observed considering a broader variety of unstructured physical activities (43.0% versus 23.5%, $p = 0.032$, $\phi = -0.19$; Figure 16).

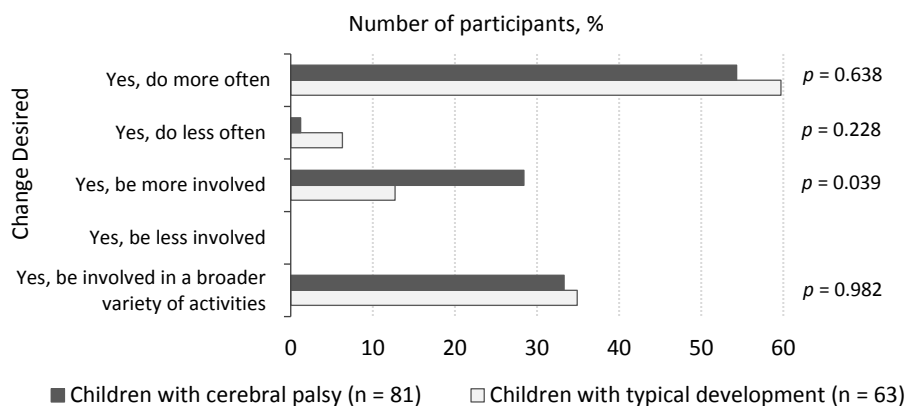


Figure 17. Classes and lessons (not school-sponsored): type of change desired

Two groups did not differ significantly concerning the type of desired change in classes and lessons that were not school-sponsored, such as music, art, languages, and computers (Figure 17). As in the previous analyses, the highest percentage of parents from both groups would like to see their child participate more frequently in this type of community-based activity (54.3% and 59.7%).

A high percentage of parents from both groups confirmed a desire for involvement in a broader variety of classes and lessons (33.3% and 34.9%). Also, 28.4% of parents of children with cerebral palsy expressed a desire for greater involvement of their child. No parents expressed a desire for a lower involvement in classes and lessons (Figure 17).

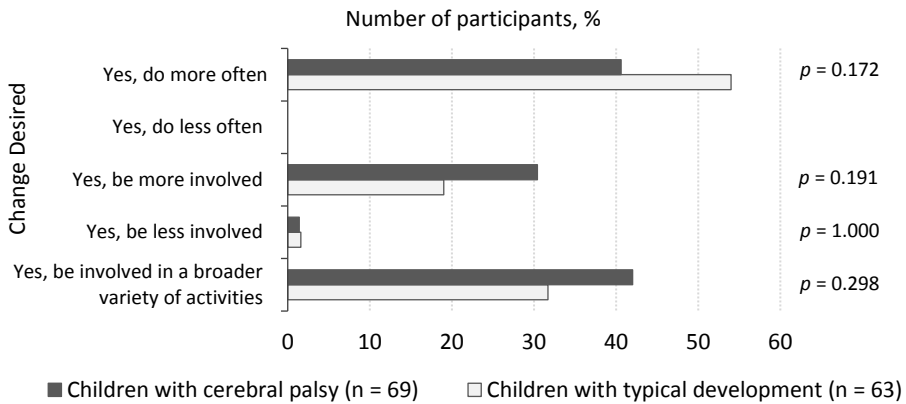


Figure 18. Organizations, groups, and clubs: type of change desired

Similarly, two groups did not differ significantly regarding the type of desired change in participation in organizations, groups, clubs, and volunteer or leadership activities (Figure 18). The highest percentage of parents from both groups would like to see their child participate more frequently here (40.6% and 54.0%).

A high percentage of parents from both groups confirmed a desire for involvement in a broader variety (42.0% and 31.7%). Also, 30.4% of parents of children with cerebral palsy expressed a desire for greater involvement of their child (Figure 18).

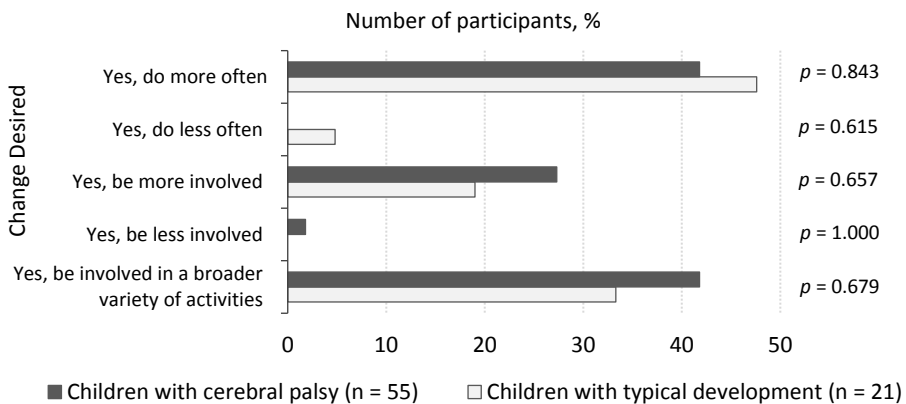


Figure 19. Religious or spiritual gatherings and activities: type of change desired

Between the two groups, the percentage of parents did not differ significantly by any type of change examined in religious or spiritual gatherings and activities, such as attending places of worship, religion classes and groups (Figure 19). The highest percentage of parents from both groups would like to see their child participate more frequently (41.8% and 47.6%) or get involved in a broader variety of activities (41.8% and 33.3%).

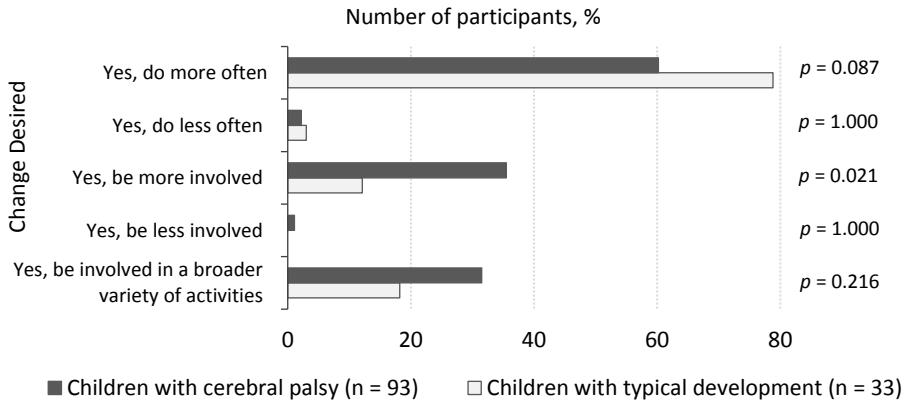


Figure 20. Getting together with other children: type of change desired

As presented in Figure 20, the highest percentage of parents from both groups would like to see their child get together with other children in the community more frequently (60.2% and 78.8%). This type of community-based activity refers to informal gatherings outside of the home or school and hanging out with other children in the community, too. Still, two groups did not differ significantly regarding the type of desired change due to the Bonferroni adjustment of the significance level.

The highest percentage of parents of children with typical development gave priority to a higher frequency, while parents of children with cerebral palsy indicated greater involvement and a wider variety of this type of activity, as well (35.5% and 31.5%). In descriptive terms, more parents of children with cerebral palsy expressed a desire for greater involvement than parents of children with typical development did (35.5% versus 12.1%, $p = 0.021$, $\phi = -0.23$; Figure 20).

When it comes to working for pay, which includes activities such as babysitting and doing chores or running errands for pay, the two groups did not differ significantly concerning the type of change desired (Figure 21). The highest percentage of parents of children with cerebral palsy gave priority to a wider variety of this type of activity (56.9%), while parents of children with typical development underlined a higher frequency, a greater involvement, and a wider variety in approximately the same percentage (36.4%, 33.3%, and 30.3%, respectively). In descriptive terms, more parents of children with cerebral palsy expressed a desire for an involvement a broader variety of activities than parents of children with typical development did (56.9% versus 30.3%, $p = 0.031$, $\phi = -0.26$).

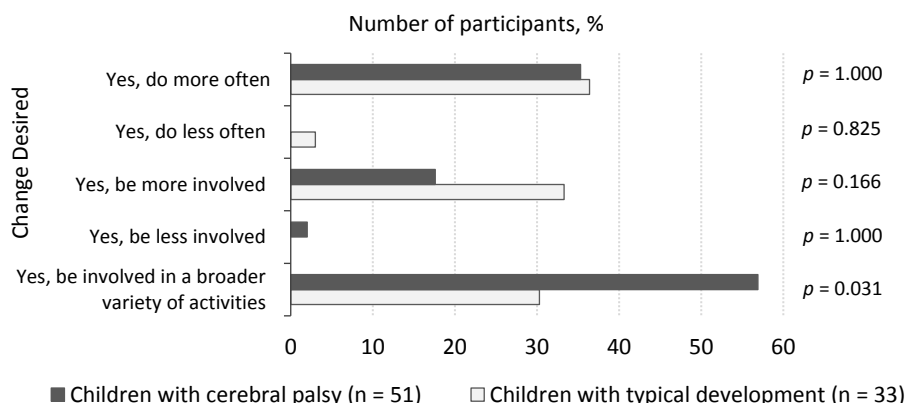


Figure 21. Working for pay: type of change desired

Between the two groups, the percentage of parents did not differ significantly by any type of change examined regarding overnight visits or trips, such as sleepovers, vacations, and camp (Figure 22). The highest percentage of parents from both groups would like to see their child participate more frequently (66.7% and 60.5%) or get involved in a broader variety of this type of activities (34.5% and 23.7%). A statistically equal percentage of parents expressed a desire for greater involvement of their children, as well (16.4% and 15.8%).

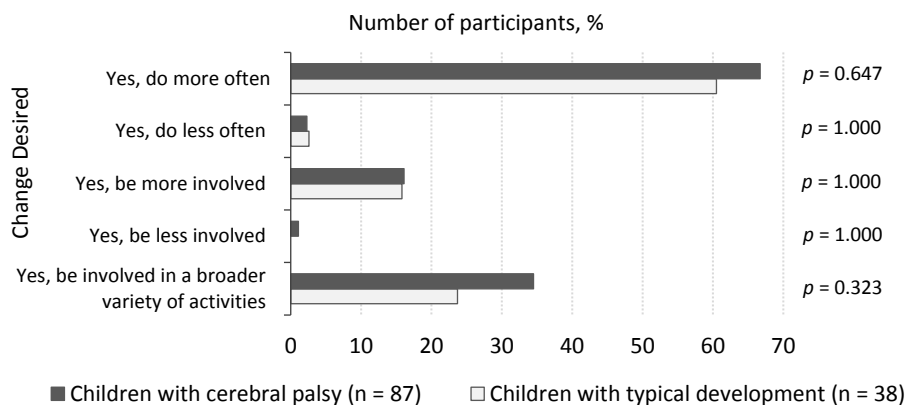


Figure 22. Overnight visits or trips: type of change desired

Take-away notes

After controlling for family income, children with cerebral palsy participated in fewer activities in the community compared to their peers with typical development.

The frequency of their participation and the level of their involvement in community-based activities are lower.

More parents of children with cerebral palsy reported that they would like to see their child's community participation change.

Higher frequency, greater involvement and a broader variety of activities are the desired types of change.

Differences between groups are also evident at the level of individual activity types, yet with a smaller effect size in frequency than in diversity and involvement.

Community environment

Table 7 presents the descriptive statistics for PEM-CY community environment summary scores and the differences between the group of children with cerebral palsy and the group of children with typical development with adjusting for family income category. Statistically significant group differences at the $p < 0.005$ and $p < 0.001$ levels were observed for all of the PEM-CY community environment summary scores.

Table 7. PEM-CY community environment summary scores: descriptive statistics and group differences

Community environment summary scores	Group	Min–Max	M (SD)	95% CI	ANCOVA	
				LL–UL	F (df1, df2)	η^2_p
Number of barriers	CP	0.00–14.00	4.27 (2.99)	3.71–4.84	104.451	0.21
	TD	0.00–4.00	0.53 (0.91)	0.37–0.69	(1, 232)**	
Number of supports	CP	0.00–12.00	4.56 (2.79)	4.04–5.09	10.400	0.04
	TD	0.00–15.00	6.42 (3.35)	5.83–7.02	(1, 232)*	
Environmental helpfulness, %	CP	33.33–100.00	73.16 (15.95)	70.15–76.18	101.874	0.31
	TD	59.26–100.00	93.87 (8.79)	92.31–95.42	(1, 232)**	
Environmental resources, %	CP	38.10–100.00	69.52 (14.18)	66.84–72.20	89.208	0.28
	TD	57.14–100.00	89.64 (9.86)	87.89–91.38	(1, 232)**	
Total environmental supportiveness, %	CP	41.67–100.00	71.57 (12.38)	69.23–73.91	146.394	0.39
	TD	60.42–15.00	92.02 (7.69)	90.65–93.38	(1, 232)**	

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; CI = confidence interval; LL = lower limit; UL = upper limit; η^2_p = partial eta squares (effect sizes) are rounded to two decimal points and interpreted as small = 0.01–0.05, moderate = 0.06–0.13 or large ≥ 0.14 . For all comparisons, Bonferroni adjustment of the significance level was set at $p < 0.01$.

* $p < 0.005$ for the total model based on analysis of covariance (ANCOVA) adjusting for family income category.

** $p < 0.001$ for the total model based on analysis of covariance (ANCOVA) adjusting for family income category.

Unadjusted means of the PEM-CY community environment summary scores were very similar to ANCOVA adjusted means in both groups, so unadjusted means are presented with their corresponding SDs (Table 7). Differences between adjusted and unadjusted means were -0.33 and 0.29 for “number of barriers”, 0.21 and -0.18 for “number of supports”, 1.08% and -0.95% for “environmental helpfulness”, 2.22% and -1.95% for “environmental resources”, and 1.58% and -1.39% for “total environmental supportiveness”, in each group, respectively (Table S8, Supplementary data).

Within a community setting, parents of children with cerebral palsy reported that the environment “usually made it harder” for their child to participate. They perceived on average 4.3 (95% CI: 3.7–4.8) environmental items as barriers (Table 7). At the same time, parents of children with typical development identified 0.5 (95% CI: 0.4–0.7) barriers to participation.

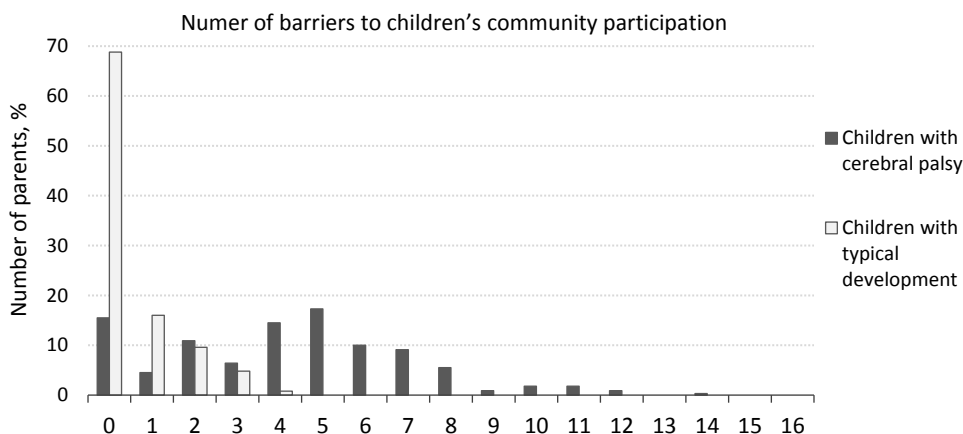


Figure 23. Number of environmental items identified as barriers to children's community participation

The difference in the distribution of the number of environmental items seen as barriers to children's community participation is given in Figure 23. In the group of children with cerebral palsy, 15.5% of parents reported no barriers, whereas 50.9% identified between four and seven. In the group of children with typical development, the majority of parents (68.8%) did not identify any environmental item as a barrier.

As presented, there are more barriers in a community setting for children with cerebral palsy compared to their peers with typical development ($p < 0.001$). Given the eta squared value of 0.21 (Table 7), it can be concluded that there is a large effect and that 21 per cent of the variance in the number of environmental items seen as barriers can be explained by the independent (group) variable

Regarding the supports in a community setting, parents of children with cerebral palsy identified on average 4.6 (95% CI: 4.0–5.1), as opposed to 6.4 (95% CI: 5.8–7.0) reported by parents of children with typical development (Table 7).

The difference in the distribution of the number of environmental items identified as supports to children's community participation is presented in Figure 24. In the group of children with cerebral palsy, more than half of parents (55.5%) reported from two to five supports, with a maximum of 12 supports. Majority of parents of children with typical development (56.8%) reported from three to seven supports, with a maximum of 15.

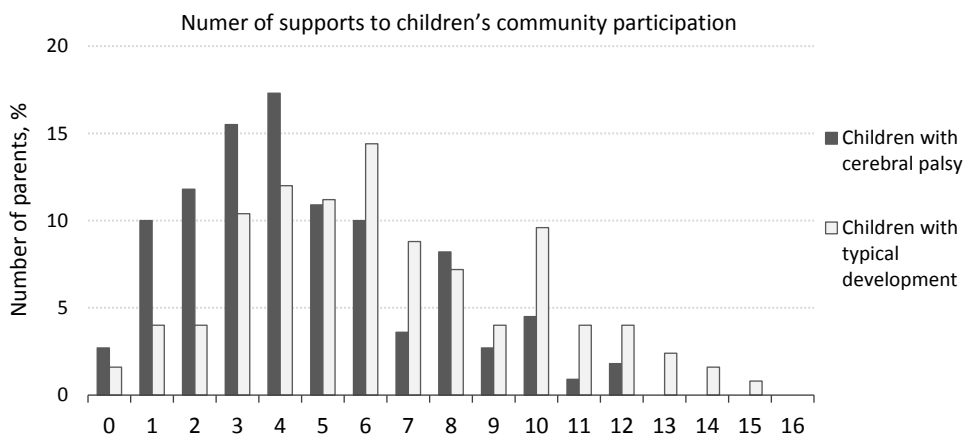


Figure 24. Number of environmental items identified as supports to children's community participation

According to the parents, there are fewer supports within a community setting for children with cerebral palsy compared to their peers with typical development ($p < 0.005$). In other words, parents of children with typical development more frequently reported that features of the environment usually helped their child's participation than parents of children with cerebral palsy. However, the magnitude of this difference is small ($\eta^2_p = 0.04$; Table 7). Expressed as a percentage, only four per cent of the variance in the number of environmental items identified as supports can be explained by the independent (group) variable.

Next, the parents' perception of how helpful the community environment was in supporting their children's participation in that setting was examined. On average, parents of children with cerebral palsy reported that the environment was less helpful ($M = 73.2\%$, 95% CI: 70.2–76.2) than parents of children with typical development did ($M = 93.9\%$, 95% CI: 92.3–95.4; Table 7).

The highest percentage of parents of children with typical development (52.8%) indicated that all environmental items were helpful in supporting their children's community participation. Contrary to that, the highest percentage of parents of children cerebral palsy (20.9%) reported that approximately 60% of environmental items were helpful (Figure 25).

It can be concluded that parents of children with cerebral palsy confirmed lower environmental helpfulness in comparison to parents of children with typical development ($p < 0.001$; Table 7). Given the eta squared value of 0.31 (Table 7), it can be concluded that there is a large effect size of this difference and that 31 per cent of the variance in the environmental helpfulness of community setting can be explained by the independent (group) variable.

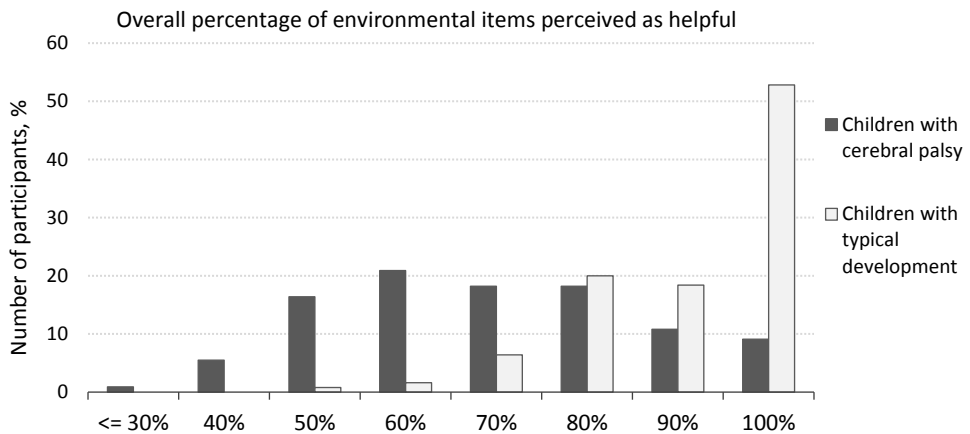


Figure 25. Environmental helpfulness: percentage of environmental items perceived as helpful in supporting community participation

When it comes to the parents’ perception of the availability of environmental resources to support their children’s community participation, the scores indicate that, on average, the resources were less available and/or adequate for children with cerebral palsy ($M = 69.5$, 95% CI: 66.8–72.2) than for children with typical development ($M = 89.6$, 95% CI: 87.9–91.4; Table 7).

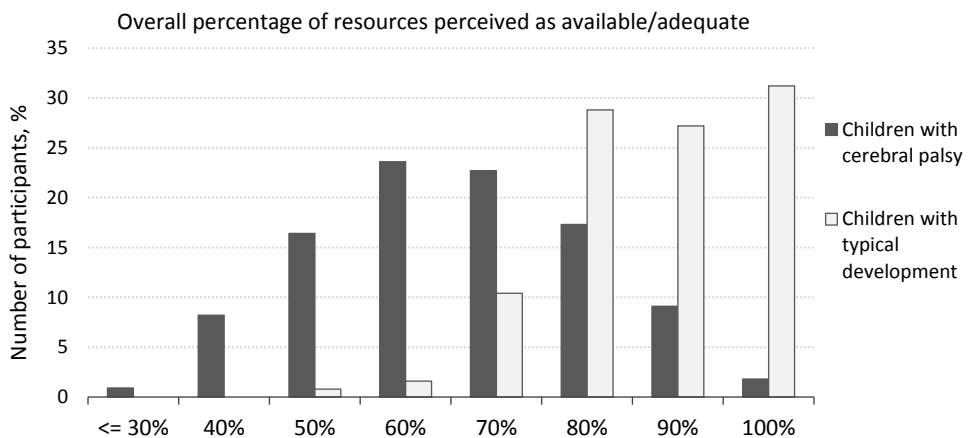


Figure 26. Environmental resources: percentage of environmental resources perceived as available/adequate to support community participation

According to the distribution of the overall percentage of resources perceived as available/adequate, 31.2% of parents of children with typical development indicated that all environmental resources were available and/or adequate to support their children’s

community participation. On the other hand, 46.3% of parents of children with cerebral palsy reported that approximately 60–80% of environmental resources were available and/or adequate (Figure 26).

Overall, resources were less available and/or adequate to support the community participation of children with cerebral palsy in comparison to children with typical development ($p < 0.001$). The eta squared statistic (0.28) indicated a large effect size (Table 7), and that 28 per cent of the variance in the total environmental helpfulness can be explained by the independent (group) variable.

The last PEM-CY community environment summary score indicates, on average, parents' overall perception of how the environment supports their children's participation in that setting (Figure 27). Higher total environmental supportiveness was calculated in the group of children with typical development ($M = 92.0$, 95% CI: 90.7–93.4) than in the group of children with cerebral palsy ($M = 71.6$, 95% CI: 69.2–73.9; Table 7).

According to the results, the community environment provided less overall support (less helpful/resources) for the participation of children with cerebral palsy when compared to children with typical development ($p < 0.001$). The eta squared statistic (0.39) indicated a large effect size (Table 7). Expressed as a percentage, 39 per cent of the variance in the total environmental supportiveness can be explained by the independent (group) variable.

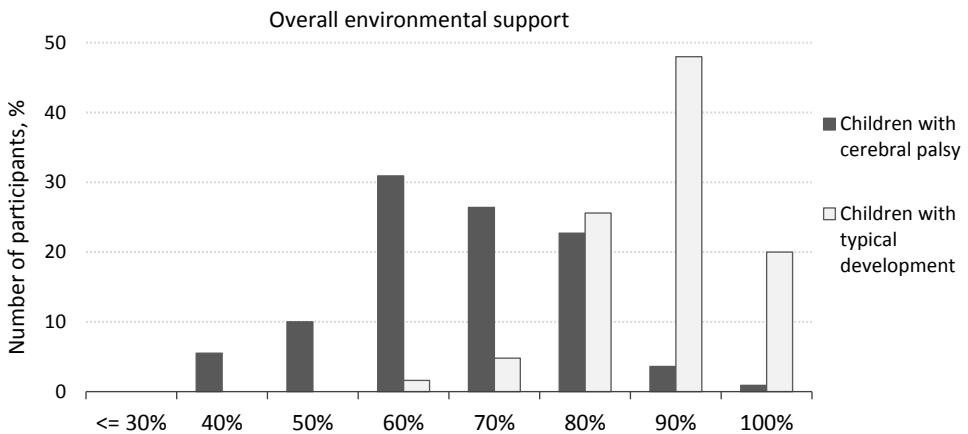


Figure 27. Total environmental supportiveness: percentage of environmental items perceived as helpful and available/adequate to support community participation

Between the two groups, the structures of environmental features were compared at the item level. First is presented the comparative review of barriers and supports within the community setting (Figures 28 to 30), followed by the comparative review of availability and/or adequacy of resources (Figures 31 to 33).

Extent of barriers and supports

Barriers, %

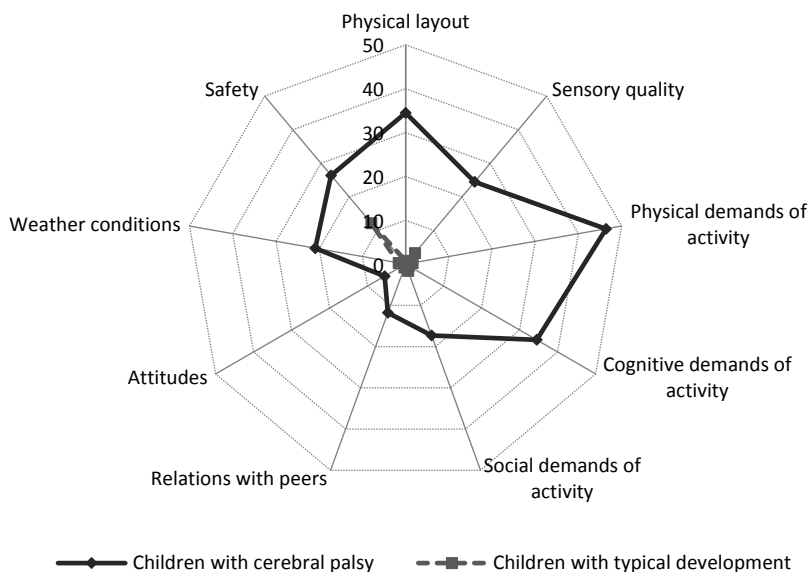


Figure 28. Percentage of parents who perceived the item as a barrier to community participation

The percentage of parents of children with cerebral palsy who perceived the item as a barrier to community participation ranged from 5.5% (attitudes and actions of others towards the child) to 46.4% (physical demands of typical activity). In the group of children with typical development, the range was from 0.0% (attitudes) to a maximum of 12.2% (safety of the community). As shown in Figure 28, group differences are particularly evident in the physical demands of typical activity (46.4% versus 1.6%), the physical layout of community settings, as well as in the cognitive demands of typical activity (34.5% versus 0.8%, both). Additionally, differences in the sensory qualities of community settings (24.5% versus 3.3%) and outside weather conditions (20.9% versus 1.6%) should be mentioned, as well.

Statistically significant differences were obtained in all community environment items perceived as barriers ($p < 0.001$, except in relations with peers at $p < 0.005$). Generally, the effect sizes (φ) were moderate. Small effect sizes were found in social demands of typical activity (-0.23) and relations with peers (-0.27), whereas the largest effect size was noted in the physical demands of typical activity (-0.53). Two community environment items in which no statistical significance was found were the attitudes and actions of other members of the community towards the child ($p = 0.027$, $\varphi = -0.17$) and safety issues ($p = 0.010$, $\varphi = -0.18$), due to Bonferroni adjustment of the significance level (Table S9, Supplementary data).

Supports, %

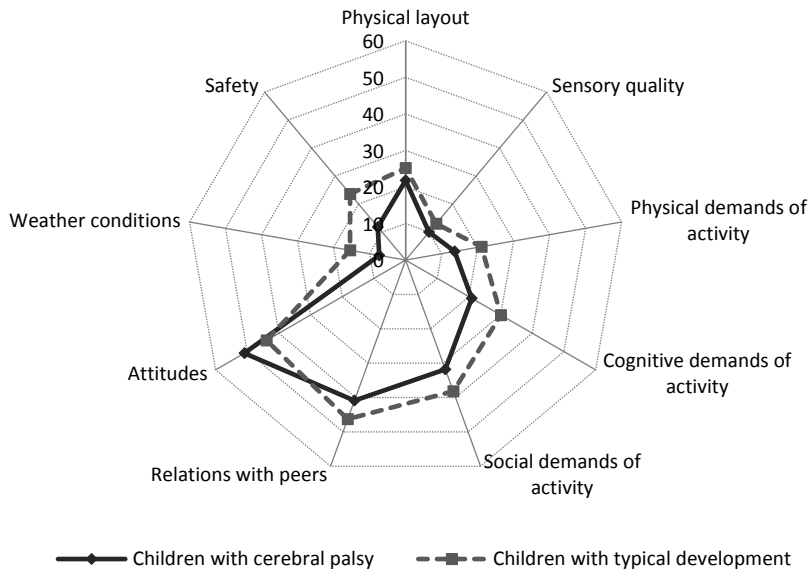


Figure 29. Percentage of parents who perceived the item as a support to community participation

Figure 29 illustrates similar patterns for children with cerebral palsy and children with typical development regarding their parents’ ratings of individual environmental items as a support to community participation. It is important to note that here no differences between the groups were found (Table S10, Supplementary data).

The highest percentage of parents of both groups stated that social demands of typical activity (31.8% and 38.2%), relations with peers (40.9% and 46.3%) and the attitudes and actions of other members of the community towards their child (50.9% and 43.9%) usually supported the child’s participation in the community. At the same time, in the lowest percentage, parents of both groups rated the outside weather conditions (7.3% and 15.4%) and sensory qualities of community settings (10.0% and 13.0%) in the same way.

The only community environment item that was rated as usually supportive in a higher percentage in the group of children with cerebral palsy than in the group of children with typical development was related to the attitudes and actions of other members of the community towards the child. More precisely, 50.9% of parents of children with cerebral palsy stated that this environmental item usually supported participation in this setting, in contrast to 43.9% of parents of children with typical development (Figure 29; Table S10, Supplementary data).

Not an Issue, %

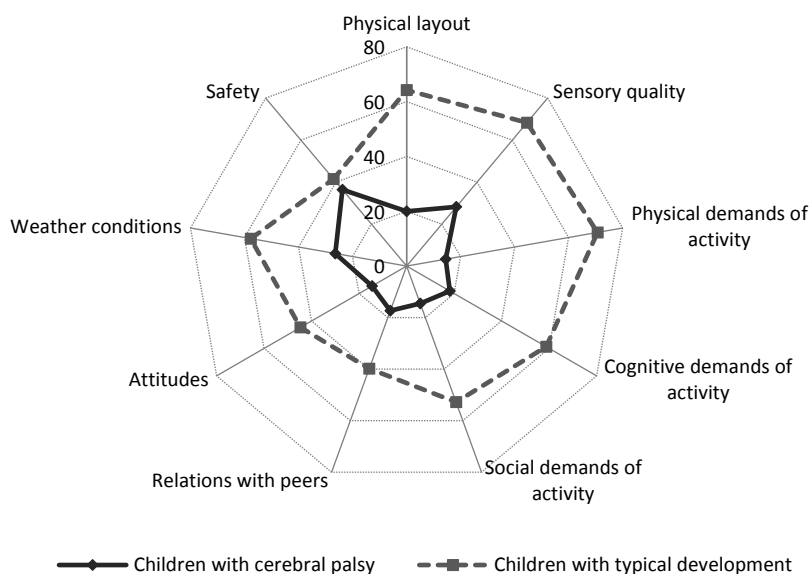


Figure 30. Percentage of parents who perceived the item as not an issue to community participation

The percentage of parents of children with cerebral palsy who perceived the item as not an issue to community participation ranged from 14.5% (found in three items: attitudes of others, physical and social activity demands) to 36.4% (safety). In the group of children with typical development, the range was from 39.8% (relations with peers) to a maximum of 70.7% (physical demands of typical activity). As shown in Figure 30, for all nine environmental items, the percentage of parents who perceived the item as not an issue to community participation was higher in the group of children with typical development.

Significantly more parents of children with typical development than parents of children with cerebral palsy reported that each feature of the environment was “not an issue” for their child to participate in the community ($p < 0.001$; Table S11, Supplementary data). The only difference that did not reach statistical significance was the difference in the domain of safety of the community ($p = 0.508$, $\phi = 0.05$). Generally, the effect sizes (ϕ) of these differences were moderate mostly, ranging from 0.32 and 0.33 (outside weather conditions and the attitudes of others) to 0.45 (physical layout of community settings). Additionally, a small effect size was found in relations with peers (0.25), whereas the largest one was noted in the physical demands of typical activity (0.55).

Availability and adequacy of resources

The percentage of parents of children with cerebral palsy who rated the resources as not available/adequate for community participation ranged from 6.4% (time to support the child’s participation) to 42.7% (programs and services). In the group of children with typical development, that same range was from 1.6% (access to personal and public transportation) to a maximum of 11.4% (programs and services).

As shown in Figure 31, group differences are particularly evident in the access to public transportation (39.1% versus 1.6%), the money to support the child’s participation (40.0% versus 2.4%), as well as in the equipment and supplies (40.0% versus 3.3%). The difference in the programs and services, e.g. inclusive sports programs, personal support worker (42.7% versus 11.4%) should be also mentioned.

Resource not available/adequate, %

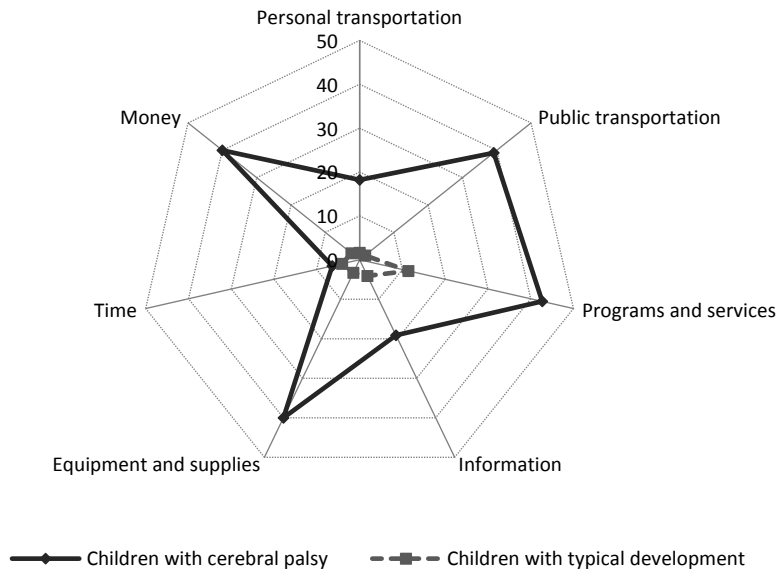


Figure 31. Percentage of parents who perceived the resource as not available/adequate for community participation

As a resource not available/adequate to support the child’s community participation, time is the only resource without statistically significant group difference ($p = 0.620$, $\phi = -0.05$). Statistically significant differences were obtained in all other items ($p < 0.001$, except for information at $p < 0.005$). Generally, the effect sizes (ϕ) were mostly moderate (Table S12, Supplementary data). Small effect sizes were found in access to personal transportation to access community activities (-0.28) and information, e.g. about activities, services, programs (-0.24). The largest effect size was noted in access to public transportation and money (-0.47, both).

Figure 32 illustrates different patterns for children with cerebral palsy and children with typical development regarding their parents' ratings of individual resources as available/adequate to support community participation. The highest percentage of parents of children with cerebral palsy (63.6%) rated the access to personal transportation as an available/adequate resource, while the highest percentage of parents of children with typical development (74.0%) rated information in the same manner (Table S13, Supplementary data). Except for programs and services, the lowest percentage of parents of both groups stated that money, as a resource, was available/adequate (20.9% and 52.8%).

Resource available/adequate, %

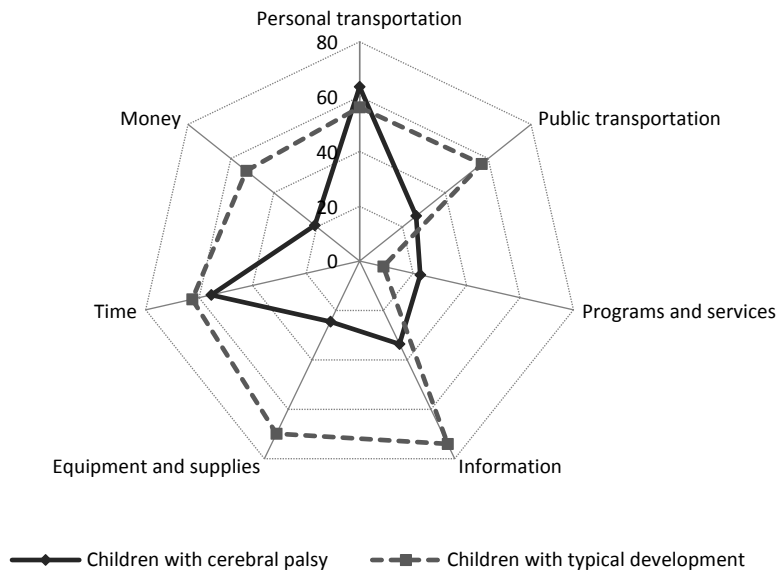


Figure 32. Percentage of parents who perceived the resource as available/adequate for community participation

No group differences were found in access to personal transportation ($p = 0.300$, $\phi = -0.08$) and time to support the child's participation in the community ($p = 0.330$, $\phi = 0.07$). Significantly more parents of children with typical development than parents of children with cerebral palsy reported that access to public transportation, information, equipment and supplies, and money were available and/or adequate as resources ($p < 0.001$, all; Table S13, Supplementary data).

The only difference that had reached the statistical significance and within which parents of children with typical development rated the resource available/adequate in a lower percentage than parents of children with cerebral palsy did was in programs and services with a small effect size (22.7% versus 8.9%, $p = 0.006$, $\phi = -0.19$). Overall, the effect sizes (ϕ) were moderate, ranging from 0.31 and 0.33 (public transportation and money) to 0.45 (equipment and supplies; Figure 32).

In the group of children with cerebral palsy, a low percentage of parents rated access to personal and public transportation (0.9% and 8.2%, respectively), and programs and services (9.1%) as not needed for their child’s participation (Table S14, Supplementary data). However, in the group of children with typical development, the percentage of parents who perceived these resources as not needed was higher, ranging from 26.8% (personal transportation) to 73.2% (programs and services; Figure 32).

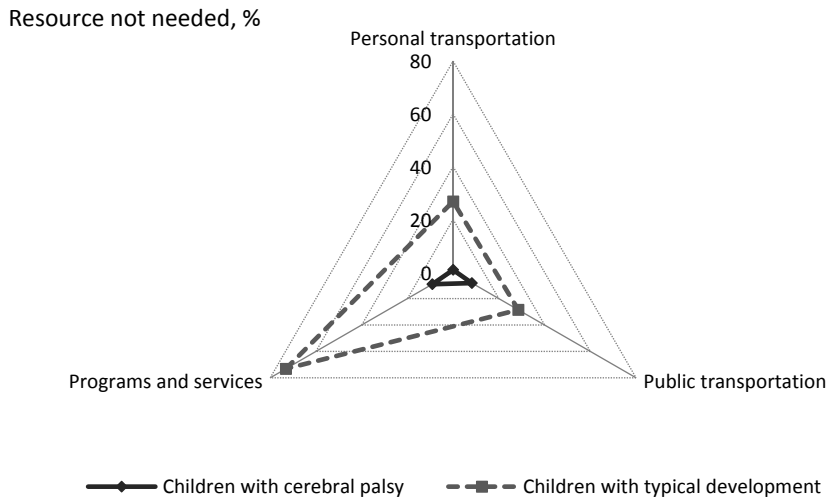


Figure 33. Percentage of parents who perceived the resource as not needed for community participation

As shown in Figure 33, for all three items, the percentage of parents who evaluated these resources as not needed to support the child’s community participation was significantly higher in the group of children with typical development ($p < 0.001$; Table S14, Supplementary data). A small effect size (ϕ) was found for the difference in access to public transportation (0.26), whereas the moderate effect size calculated for access to personal transportation (0.37). The large effect size was noted in the availability/adequacy of programs and services (0.65).

Take-away notes

After controlling for family income, there were more barriers and fewer supports in a community setting for children with cerebral palsy than for their peers with typical development.

Parents of children with cerebral palsy reported lower overall environmental supportiveness than parents of children with typical development did. More specifically, less available and/or adequate resources and less helpful environment to support children's community participation were confirmed.

Areas identified as the greatest barriers for children with cerebral palsy included physical and cognitive demands of the activity and physical layout of community settings, whereas the greatest supports included attitudes of others, relationships with peers and social demands of the activity.

Although parents of children with cerebral palsy rated environmental factors as support less frequently than parents of children with typical development did, there were no significant group differences.

Parents of children with cerebral palsy stated that key resources (public transportation, money, equipment and supplies, programs and services) were usually unavailable or inadequate.

Relationship between community participation characteristics and functional limitations of children with cerebral palsy

Community participation, including environmental features, was explored in relation to gross motor functioning (GMFCS level), fine manual abilities (MACS level) and the level of intellectual functioning. There were small, negative correlations between the involvement level and both GMFCS ($\rho = -0.30, p < 0.01$) and MACS level ($\rho = -0.26, p < 0.01$), with higher levels of functional limitations associated with lower involvement in community-based activities (Table 8). Additionally, there was a small, negative correlation between MACS level and participation frequency ($\rho = -0.21, p < 0.05$), indicating that lower frequency was associated with more severe limitations of fine manual abilities. Two moderate, negative correlations were calculated in regard to the level of intellectual functioning. The first correlation was confirmed for the percentage of children that participated in activities ($\rho = -0.33, p < 0.01$), whereas the second one was found related to the level of involvement ($\rho = -0.40, p < 0.01$). In other words, diversity and involvement level were associated with the severity of intellectual impairment.

On the other hand, there were no statistically significant correlations between GMFCS level and features of community environment (Table 8). When it comes to MACS level, only one statistically significant correlation was confirmed, related to the environmental resources. This small, negative correlation ($\rho = -0.21, p < 0.05$) indicates a weak association between fine manual limitations and percentage of environmental resources perceived as available/adequate to support participation. The level of intellectual functioning correlated with the number of supports ($\rho = -0.21, p < 0.05$), environmental helpfulness ($\rho = -0.21, p < 0.05$), and the overall environmental supportiveness ($\rho = -0.21, p < 0.05$), indicating weak association between the severity of intellectual impairment and some features of the community environment.

Table 8. *Relationship between community participation pattern and features of the community environment and functional limitations of children with cerebral palsy*

Community participation and environment scores	GMFCS	MACS	Intellectual functioning
Participates ever, %	-0.180	-0.098	-0.328 **
Participation frequency	-0.097	-0.213 *	0.181
Level of involvement	-0.297 **	-0.255 **	-0.399 **
Number of barriers	0.080	0.105	0.142
Number of supports	0.008	-0.153	-0.206 *
Environmental helpfulness, %	-0.002	0.045	-0.215 *
Environmental resources, %	-0.128	-0.206 *	-0.116
Total environmental supportiveness, %	-0.058	-0.071	-0.208 *

Note. Intellectual functioning is categorized as normal (1) and borderline intellectual functioning (2), mild (3), moderate (4), and severe intellectual disability (5). Presented are the coefficients of Spearman's rank correlation, interpreted as small (0.10–0.29), moderate (0.30–0.49) or strong (0.50–1.00).

* $p < 0.05$, two-tailed. ** $p < 0.01$, two-tailed.

Participates ever, %

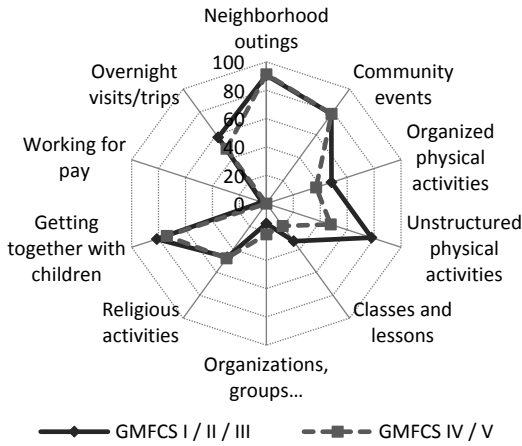


Figure 34. Diversity of community participation in relation to gross motor functioning (GMFCS) of children with cerebral palsy

In general, there was no significant difference in the gross motor functioning of children with cerebral palsy who had participated in a specific type of activity and those who did not, except for unstructured physical activities (Figure 34). Fifty (78.1%) children with milder gross motor impairment (GMFCS levels I/II/III) had participated in unstructured physical activities, in contrast to 22 (47.8%) children with severe gross motor limitations (GMFCS levels IV/V), with a moderate effect size, $\chi^2(1, N = 110) = 9.57, p = 0.002, \phi = -0.31$ (Table S15, Supplementary data).

Analysis of differences related to the manual abilities of children with cerebral palsy gave a comparable outcome (Figure 35). The only activity that had reached the adjusted significance level was in unstructured physical activities. In contrast to 22 (45.8%) children with more severe limitations in manual functions (MACS IV/V), there were 50 (80.6%) children with milder forms (MACS I/II/III) that had participated also in these unstructured physical activities, $\chi^2(1, N = 110) = 13.00, p < 0.001, \phi = -0.36$ (Table S16, Supplementary data).

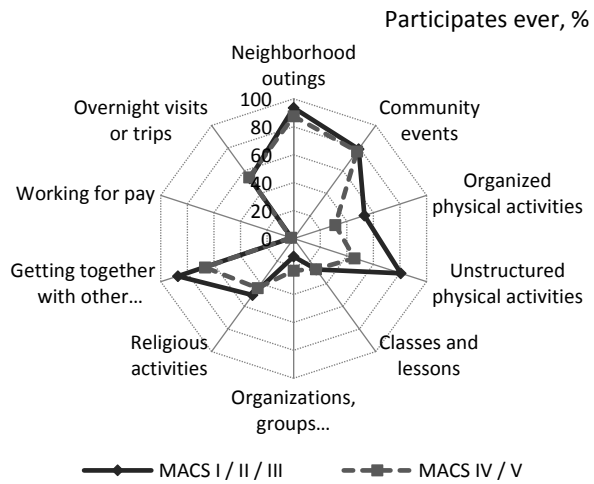


Figure 35. Diversity of community participation in relation to fine manual abilities (MACS) of children with cerebral palsy

Two other differences in community participation related to the manual abilities should be noted, yet with no statistical significance due to Bonferroni adjustment of the significance level. In both, it was found that more children with milder forms (MACS I/II/III) had participated in comparison to children with more severe limitations in manual functions (MACS IV/V). The first difference is noted in the organized physical activities, 53.2% versus 31.3%; $\chi^2 (1, N = 110) = 4.46, p = 0.035, \phi = -0.22$. The second one is calculated for getting together with other children, 87.1% versus 66.7%; $\chi^2 (1, N = 110) = 5.48, p = 0.019, \phi = -0.25$ (Table S16, Supplementary data).

Differences in community participation were explored in comparison to the level of intellectual functioning (Figure 36). In organized physical activities, more children with normal or borderline intellectual functioning (47.2%), as well as children with mild intellectual disability (64.5%) had participated compared to children with moderate or severe intellectual disability (25.6%). As calculated, this difference was statistically significant with a moderate effect size, $\chi^2 (2, N = 110) = 11.38, p = 0.003, V = 0.32$ (Table S17, Supplementary data).

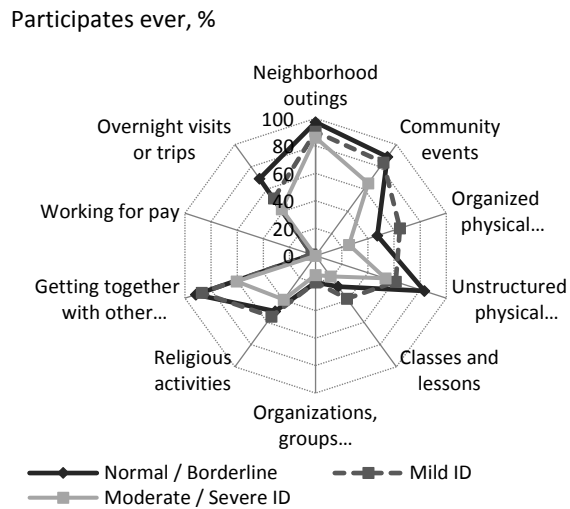


Figure 36. Diversity of community participation in relation to the level of intellectual functioning or intellectual disability (ID) of children with cerebral palsy

A similar distribution was found regarding informal gatherings outside of the home or school, hanging out with other children in the community or getting together with other children. More children with normal or borderline intellectual functioning (91.7%) and mild intellectual disability (87.1%) had participated in activity than children with a moderate or severe intellectual disability did (60.5%), with statistically significant difference with a moderate effect size, $\chi^2 (2, N = 110) = 13.19, p = 0.001, V = 0.35$ (Table S17, Supplementary data).

In community events, children with normal or borderline intellectual functioning (88.9%) and mild intellectual disability (83.9%) participated in a higher percentage that children with a moderate or severe intellectual disability did (65.1%), yet with no statistical significance due to Bonferroni adjustment of the significance level, $\chi^2 (2, N = 110) = 7.31, p = 0.026, V = 0.26$. A comparable trend was observed in unstructured physical activities, $\chi^2 (2, N = 110) = 8.05, p = 0.018, V = 0.27$ (Table S17, Supplementary data). Only one-half of the children with a moderate or severe intellectual disability participated (53.5%), in contrast to children with normal or borderline intellectual functioning (83.3%).

Two coefficients of correlation between the frequency of participation in each community-based activity and functional limitations of children with cerebral palsy were statistically significant (Table S18, Supplementary data). Frequency of participation in organized physical activities was in a moderate, negative correlation with the MACS level ($\rho = -0.36, p < 0.05$), with more severe fine manual limitations associated with a lower frequency (Figure 37).

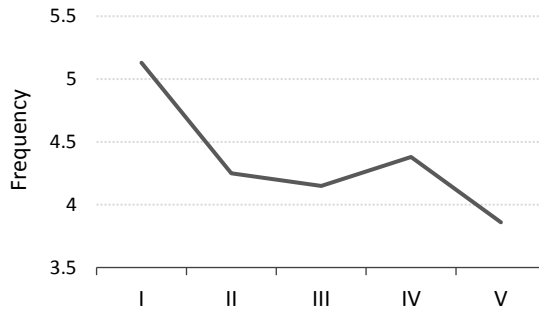


Figure 37. Frequency of participation in organized physical activities in relation to the MACS level

Moreover, there was a moderate, negative correlation between the level of intellectual functioning and the frequency of participation in organized physical activities ($\rho = -0.41, p < 0.05$). Higher frequency of participation was associated with higher levels of intellectual functioning (Figure 38).

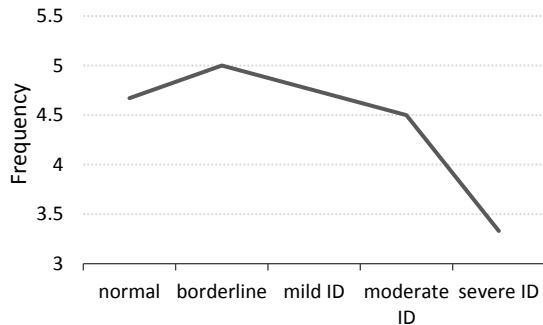


Figure 38. Frequency of participation in classes and lessons in relation to the level of intellectual functioning

Functional limitations of children correlated with the level of involvement in some community-based activities (Table S19, Supplementary data). More precisely, GMFCS level in a moderate, negative correlation with the involvement in neighbourhood outings ($\rho = -0.30, p < 0.01$) and in a small, negative correlation with the unstructured physical activities ($\rho = -0.27, p < 0.05$). This result suggests that children with more severe gross motor limitations were less involved in these two activities (Figure 39).

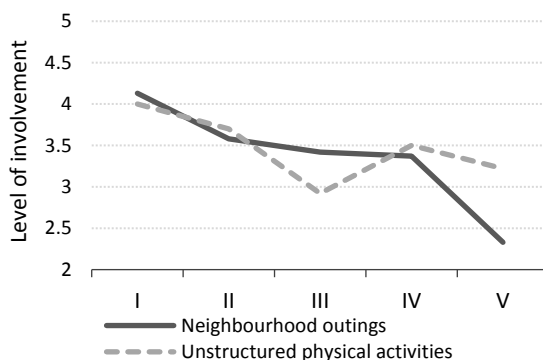


Figure 39. Involvement in neighbourhood outings and unstructured physical activities in relation to the GMFCS level

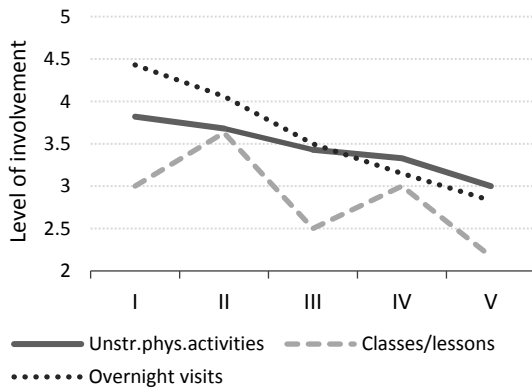


Figure 40. Involvement in unstructured physical activities, classes and lessons and overnights visits in relation to the MACS level

Next, MACS level was in moderate, negative correlations with the level of involvement in unstructured physical activities ($\rho = -0.30, p < 0.05$), classes and lessons ($\rho = -0.48, p < 0.01$), and overnight visits or trips ($\rho = -0.33, p < 0.05$; Table S19, Supplementary data). According to these results, more severe limitations in fine manual abilities were associated with a lower level of involvement in unstructured physical activities, classes and lessons and overnight visits or trips (Figure 40).

Several coefficients were statistically significant when the relationship between the levels of involvement in community-based activities and intellectual functioning was analysed (Figure 41; Table S19, Supplementary data).

These are the following: neighbourhood outings and community events ($\rho = -0.39, p < 0.01$, both), unstructured physical activities ($\rho = -0.28, p < 0.05$), classes and lessons ($\rho = -0.46, p < 0.05$) and getting together with other children ($\rho = -0.31, p < 0.01$). Similar to previous findings, the severity of intellectual impairment was associated with a lower level of involvement in neighbourhood outings and community events, unstructured physical activities, classes and lessons and getting together with other children (Figure 41).

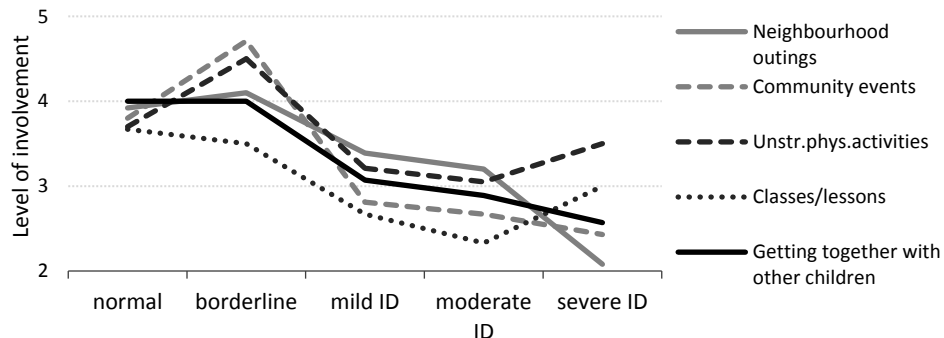


Figure 41. Involvement in selected community activities in relation to the level of intellectual functioning

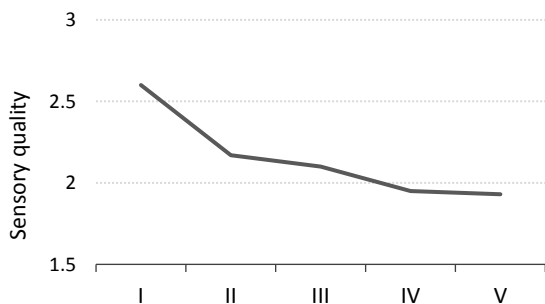


Figure 42. The sensory qualities of community settings in relation to the GMFCS level

When it comes to the features of environmental helpfulness, small, negative correlation between the sensory quality of community settings and GMFCS level ($\rho = -0.19$, $p < 0.05$) indicates that higher levels of gross motor limitations are associated with sensory qualities of community settings rated as less helpful in supporting the child's participation in that setting (Figure 42; Table S20, Supplementary data).

The level of intellectual functioning was in small, negative correlations with social demands of typical activities ($\rho = -0.25$, $p < 0.01$) and outside weather conditions ($\rho = -0.23$, $p < 0.05$), and in a moderate, negative correlation with cognitive demands ($\rho = -0.33$, $p < 0.01$). In more severe levels of intellectual impairment, social and cognitive demands of typical activities and outside weather conditions were rated as harder for the child to participate in the community (Figure 43; Table S20, Supplementary data).

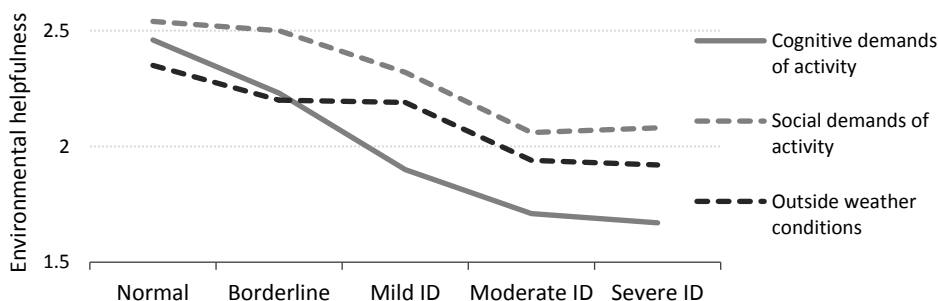


Figure 43. Features of environmental helpfulness in relation to the level of intellectual functioning

Regarding relationship between the environmental resources and functional limitations, two correlations were statistically significant. More severe gross motor ($\rho = -0.24$, $p < 0.05$) and fine manual limitations ($\rho = -0.28$, $p < 0.01$) were associated with unavailable and/or inadequate access to public transportation (Figure 44; Table S20, Supplementary data).

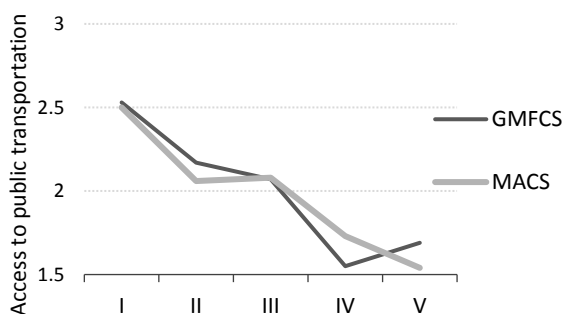


Figure 44. Access to public transportation in relation to the GMFCS and MACS levels

Take-away notes

Higher levels of functional limitations (gross motor functioning, fine manual functioning and intellectual functioning) of children with cerebral palsy were associated with lower involvement in community-based activities. On the other hand, more severe limitations of fine manual abilities were associated with lower frequency.

Both diversity and involvement were associated with intellectual functioning, indicating that children with more severe levels of intellectual disability participated in fewer community-based activities and/or with lower involvement levels. Level of intellectual functioning was also in weak association with some features of the community environment.

Activities affected by functional limitations are unstructured and organized physical activities, getting together with other children, and to a lesser extent, community events, neighbourhood outings, overnight visits/trips and classes and lessons.

More severe levels of intellectual impairment were associated with social and cognitive demands of typical activities and outside weather conditions rated as harder for the child to participate in the community.

More severe gross motor and fine manual limitations were associated with unavailable and/or inadequate access to public transportation.

DISCUSSION

Characteristics of community participation

This study aimed to examine the characteristics of community participation of children with cerebral palsy in comparison to their peers with typical development and the effect of the environment on this participation, from the perspective of parents.

The first research question referred to the differences in participation in community-based activities between the two groups of children, children with cerebral palsy and children with typical development. It was hypothesized that there were differences in characteristics of participation in community-based activities between children with cerebral palsy and children with typical development.

According to the results, the participation of children with cerebral palsy and children with typical development in the community environment has reached the level of statistical significance in all tested summary scores ($p < 0.001$; Table 6). More precisely, children with cerebral palsy participated in a smaller number of community-based activities ($\eta^2_p = 0.22$), the frequency of their participation was lower ($\eta^2_p = 0.09$), as well as the level of involvement ($\eta^2_p = 0.37$). In line with the findings from previous research studies, we may conclude that the overall participation of children with cerebral palsy in the community environment is lower compared to the participation of their typically developing peers (Bedell et al., 2013; Coster et al., 2011).

Differences between the findings of different studies can, however, be primarily observed in the calculated effect sizes. In our research, they are the largest in the children's level of involvement, and the smallest in the frequency of community-based activities. Somewhat similar results were obtained in the only published study so far regarding the participation of children with disabilities in the community, where the focus was on the same characteristics of participation patterns included in our research. More specifically, Bedell et al. (2013) reported that statistically, the largest effect sizes were also in the level of involvement, and the lowest in the diversity of activities. Compared to the results of our research, there are several similarities when it comes to the individual dimensions of participation patterns in the community of children with cerebral palsy and school-age children with a broad range of disabilities, but also children from the typical population. In the first place, the diversity of types of activity the children with cerebral palsy from our research are included in is smaller when compared to children with a broad range of disabilities. Data indicate that there is a greater percentage of activities in which children with cerebral palsy never participate (49.64 versus 41.49). Additionally, the average frequency and level of involvement in activities of all participants in our research are somewhat higher (4.20 versus 3.79 and 3.16 and 3.55, respectively). Moreover, the children with typical development from our research were included in a higher involvement level (4.63 versus 4.17) than the children with

typical development, as reported by Bedell et al. (2013). In contrast, a lower involvement level was noted in children with cerebral palsy from our research than their peers with a broad range of disabilities included in the above-mentioned research (3.16 versus 3.55). These differences may be the consequence of different age structure of the samples; participants included in our research were slightly older (12.7 and 12.0 years of age versus 11.7 and 10.6 years of age) with the age range however mostly overlapping (7–18 versus 5–17 years). Recently, it was confirmed that children with disabilities experienced greater restriction in community-based participation compared to peers without disabilities. Participation patterns were similar, yet the extent to which children with and without disabilities participated in each activity differed (Arakelyan et al., 2020).

Overall, children with a broad range of disabilities participated in the above-mentioned research and the results were summarized, i.e. the results of the sub-group of participants with cerebral palsy were not separated, thus rendering direct comparison of result values impossible. Apart from the ones mentioned, other differences might include the families' everyday life tempo, different family and community life dynamics but also cultural differences which are not the subject of our research. Finally, Coster et al. (2011) presented comparable results and identical conclusions in a previously published article based on a preliminary analysis of the data collected in the same research.

Comparison of participation by individual community-based activities

When it comes to individual types of community-based activities, the diversity is lower in the group of children with cerebral palsy than in the group of children with typical development (Table S2, Supplementary data). The only exceptions are religious or spiritual gatherings and activities in which a lower percentage of children with typical development have participated in, yet without the statistical significance of that difference (40.0% versus 47.3%) and neighbourhood outings, in which no statistical significance was found (90.9% to 98.4%).

In our research, the lowest percentage of children with cerebral palsy participated in paid work or was involved in household chores or other tasks for pocket money at least once in the last four months (1.8%), they also did not participate in the work of youth organisations or clubs, public performances, or volunteer activities (82.7%). There is also a low percentage of those who attended extracurricular classes or courses, such as foreign language or computer courses (27.7%). On the other hand, the largest percentage of children with cerebral palsy took part in neighbourhood outings, went to a store or a mall (90.9%); in other words, those are the community-based activities the greatest number of them participates in at least once in four months. Our data are directly comparable to those presented by Longo et al. (2013), according to which 95% of children with cerebral palsy never engage in volunteer activities, 80% of them do not participate in the work of local community organisations, while only 1.5% of them perform some form of paid work. Furthermore, the same authors have identified three leisure activities, i.e. spontaneous socialisation / hanging out (92.5%), visiting (87.9%),

and entertaining others (85.9%), as informal activities in which the greatest percentage of children with cerebral palsy participate. Regarding leisure activities, which primarily take place outside the immediate home and school environment, participants with cerebral palsy from their research engage, in highest percentage, in gymnastics (59.8%), swimming (55.8%) and team sports (27.6%) as formal and organised activities (Longo et al., 2013). Other authors have reported somewhat different representation of children with cerebral palsy who never take part in organised physical activities (45.5%), do not attend classes and lessons that are not school-sponsored (57.6%) or take part in club activities (54.5%) (Radulović et al., 2014).

As parents of children with typical development from our research have reported, the lowest percentage of their children were also involved working for pay, doing household or other chores for pocket money (17.6%) or taking part in youth organisations and club activities, public events or volunteer activities (48.0%). More than half have also never attended religious or spiritual gatherings and do not visit religious institutions or extracurricular religion classes (60.0%). However, almost all children from this group participated at least once in four months in the following four out of ten types of community activities: neighbourhood outings, community events such as shows or concerts, unstructured physical activities such as cycling and roller skating, ball games, and socialising with other children in the community (98.4% each). Differences between the groups are particularly statistically evident in the area of organised physical activities ($\varphi = 0.48$), language or computer classes, and extracurricular courses ($\varphi = 0.45$) and unstructured physical activities ($\varphi = 0.44$; Table S2, Supplementary data). The trend of higher diversity in informal activities than in formal activities, i.e. higher diversity in social and recreational than in skill-based, self-improvement and active physical leisure activities is in line with previous scientific reports (Longo et al., 2013; Majnemer, Shevell, Law, Birnbaum, et al., 2008). Besides, by comparing the distribution of our results with the results of the study by Bedell et al. (2013), it can be concluded that participation of children with cerebral palsy from our research and their typically developing peers is comparable, across all characteristics, with the participation of children with a broad range of disabilities and their typically developing peers. The only difference is that, in the mentioned research, a lower percentage of participation in all types of activities is confirmed in the group of children with a broad range of disabilities, while in our research the direction is different when it comes to religious and spiritual activities; however, neither research confirmed the statistical relevance of this trend.

When it comes to frequency of participation in relation to the type of community-based activities, children with typical development participate more frequently in all ten types of activities, with the statistical significance of difference confirmed for only four (Table S3, Supplementary data). Statistically speaking, the greatest difference is in socializing with other children in the community and spontaneous gatherings ($\eta^2_p = 0.15$). Moderate effect sizes differences were also confirmed in frequency of organised ($\eta^2_p = 0.07$) and unstructured physical activities ($\eta^2_p = 0.06$) and attendance of shows, concerts, sports events or going for walks ($\eta^2_p = 0.09$). In all other types of community activities, there was no statistical significance difference between groups.

In descriptive terms, children with cerebral palsy from our research have most frequently, i.e. once a week, participated in neighbourhood outings and unstructured physical activities; in those same activities, children with typical development were engaged a few times a week usually, and they often socialise with other children in the community. Both groups had the least frequency of overnight visits or trips, several times over four months. Bedell et al. (2013) had similar findings, yet without statistical significance in differences between neighbourhood outings and overnight visits or trips, whereas participation of children with a broad range of disabilities in other types of activities was mainly comparable to our findings. However, it must be emphasized that our participants with cerebral palsy had less frequently participated in all activities compared to their typically developing peers. As opposed to that, children with a broad range of disabilities participated more frequently than their typically developing peers in club or organisation activities, they were engaged in volunteer activities and house chores for pocket money more often, although without the statistical significance of the difference (Bedell et al., 2013). In our research, parents of children with cerebral palsy have reported more frequent socialising of their children with other children in the community than parents of children with a broad range of disabilities (4.6 versus 3.9 at the seven-point Likert type scale), more frequent attendance at community events such as shows or concerts (3.9 versus 2.8), and also more frequent neighbourhood outings and unstructured physical activities (5.4 versus 4.9, and 5.1 versus 4.5, respectively). Similarly, children with typical development from our research socialised more frequently with other children (5.9 versus 5.0) and attended community events more frequently than the children with typical development in the mentioned research did (5.0 versus 3.3). Contrary to that, children with cerebral palsy and children with typical development from our research participated less frequently in the following two types of activities with a descriptively greatest difference: organizations, groups, clubs, and volunteer or leadership activities (3.0 and 3.2 versus 3.9, both) and religious or spiritual gatherings or activities (3.1 and 3.5 versus 3.6 and 4.2). Moreover, earlier researchers (Parkes et al., 2010) pointed to the statistical significance of the difference in frequency of participation in the work of local community organisations, going to sports, art or cultural events as being more frequent in children from the typical population, aged eight to 12, compared to their peers with cerebral palsy. As noted previously, greater frequency trend in informal rather than formal activities, i.e. greater frequency in social and leisure unstructured activities than in those related to skills, self-improvement and active physical activities has been consistent with scientific reports so far (Grbović et al., 2012; Longo et al., 2013; Majnemer, Shevell, Law, Birnbaum, et al., 2008). Grbović et al. (2012) reported that the least frequent community-based activities of young people with cerebral palsy aged 11 to 19 included winter sports, participation in the work of organisations, attending instrument-playing lessons, engaging in paid and volunteer work, then going to various celebrations and events. Regarding community activities, according to the presented data, religious activities and going for walks may be described as frequent.

The third characteristic of participation is related to the level of involvement in the community environment. The mean involvement level of children with cerebral palsy is lower than the one of children with typical development in all types of community

activities (Table S6, Supplementary data). Statistically, the greatest differences in the involvement level in relation to the type of activities are in socialising with other children ($\eta^2_p = 0.32$) and community events ($\eta^2_p = 0.32$), followed by unstructured physical activities ($\eta^2_p = 0.32$). However, there are certain differences concerning the population of children with a broad range of disabilities. More precisely, as reported by Bedell et al. (2013), children with disabilities were more involved in paid activities such as doing household chores for pocket money, and a statistical significance was found when their score was compared to the score of their typically developing peers, although with the small effect size ($\eta^2_p = 0.00$, $p = 0,001$). Also, according to these authors' findings, there are no differences in the level of involvement when it comes to classes or courses outside school and religious or spiritual gatherings and activities. Sizes of determined differences, however, have a moderate effect; they are the greatest in unstructured physical activities ($\eta^2_p = 0.10$, $p = 0,001$), but also in socialising with other children in the community and community events ($\eta^2_p = 0.09$, $p = 0,001$, both), which is comparable to our findings.

According to obtained results, when regarded as a whole, at the level of all individual types of activities in the community environment, one can conclude that children with cerebral palsy participate less frequently and that they are less involved than their typically developing peers are. Moreover, a large percentage of them never participate in the explored activities. Religious or spiritual gatherings and activities where a higher percentage of children with typical development never participate are an exception, although without a statistical significance. Activities in which a small percentage of children with cerebral palsy participate are mostly organised, formal, structured and physically and/or cognitively more demanding – paid work, volunteering, engagement in organisations, groups or clubs, attending foreign language schools or sports, music lessons, arts or computer lessons, visiting religious facilities or attending extracurricular religion classes. Previous studies have reported similar findings. Children with disabilities participated with lower frequency in unstructured and organized physical activities, religious gatherings and getting together with friends (Arakelyan et al., 2020). This trend was explained by a smaller likelihood of participation in informal activities being under the negative influence of barriers (Longo et al., 2013). As noted, children with cerebral palsy would rather participate in more spontaneous activities, activities that are more accessible in their environment and closer to them, such as neighbourhood outings, going to shops, malls, and cinemas or to see shows and socialising with other children in the community. On the other hand, in one study, it was shown that children with physical and neurological disabilities enjoyed the same activities as those children without these disabilities and being with others was acknowledged as important for successful participation (Heah et al., 2007). This finding is underlined as relevant because only activities that allow children to experience enjoyment while participating have the best chance to ensure children's participation.

These findings empirically prove and point to the conclusion that a great number of children with cerebral palsy are still excluded from community activities in our environment. In line with our previous finding, diversity of overall participation and participation in individual activities in the community is lower than in the home setting (Milićević, 2020; Milićević & Nedović, 2018). As a comparison, children with severe

intellectual and multiple disabilities are also least present in the activities taking place outside the family environment, which includes outdoor activities, organised activities, and family outings (Axelsson & Wilder, 2014). The earlier data also pointed to the overall lower participation in those activities that were taking place at the community level (Majnemer, Shevell, Law, Birnbaum, et al., 2008). Similarly, previous research studies have reported that children with motor disorders, including children with cerebral palsy, were participating less frequently in formal than informal activities, with smaller diversity of the community-based activities (Brown & Gordon, 1987; Law et al., 2006; Longo et al., 2013). Some authors believe that environmental barriers are more frequently encountered and more difficult to predict or modify than those in the home setting (Bedell et al., 2013; Bedell & Dumas, 2004; Law et al., 2007).

One possible explanation could be cultural similarities and/or differences, and geographic variations as well. That way, differences between diversity and frequency of participation of children with cerebral palsy and children from the typical population aged six to 20 living in the territories of Australia, Canada and the United States of America have been explained (King et al., 2013), and also aged eight to 12 living in seven European countries (Fauconnier et al., 2009; Michelsen et al., 2009). Besides, a child and parents' preferences, which have not been part of our research, may also have an influence. It has previously been demonstrated that preferences partly determine the diversity of participation of children with cerebral palsy aged between 10 years 9 months and 12 years 9 months (Imms et al., 2009). Also, a review of the structure of environmental factors in a corresponding setting might provide additional answers, primarily the existence and availability of services, availability of transportation, accessibility of facilities, and similar features (Bedell & Dumas, 2004; Imms et al., 2009).

It is noteworthy that, in summary, almost half of the children with cerebral palsy who participated in the research never take part in community activities. However, excluding the activities they never participate in, children with cerebral palsy less frequently participate in four out of ten types of activities, with a moderate to large effect sizes.

In conclusion, the key difference in the characteristics of community participation between two groups of children is evident in the child's level of involvement. In other words, many activities in the community do occur with comparable frequency, but with minimal or partial involvement of children with cerebral palsy, while their typically developing peers are involved to a level nearing a maximum involvement. Most of the actual differences between the values of overall participation and participation in individual activities are in favour of such a trend.

The results confirmed that the differences between the two groups of children were evident at the activity level, particularly when comparing involvement level, and that the least differences were obtained in activities that typically did not require much physical engagement. Corresponding to participation in home settings, the frequency of occurrence of certain community-based activities should not be observed apart from other characteristics of participation (Hammel et al., 2008; Imms, 2020; Imms et al., 2016, 2017; Milićević, 2020). In other words, information about whether a child with cerebral palsy participates in certain types of activities or not and, if it does – how often

the child participates and to what level it is included, may create a semblance of its (in)complete involvement in that environment.

Parent's satisfaction with the child's current participation

Parents of children with cerebral palsy expressed their desire for a change of participation in a greater number of activities than the parents of children with typical development did ($p < 0.001$, $\eta^2_p = 0.27$; Table 6). Therefore, it may be concluded that the overall satisfaction of parents of children with cerebral palsy with the child's current participation is significantly lower compared to that of parents of children with typical development (72.6% versus 35.8%). Parents of their children with cerebral palsy emphasized more frequent and varied activities, with a higher level of involvement of their children as desired changes. In contrast, in the group of children with typical development, parents mostly did not report that change was needed (Figure 8).

A similar trend can also be found in other studies. Previously, parents of children with a broad range of disabilities have expressed their desire for a change of participation in 63.2% of the community activities, statistically significantly more than parents of children without disabilities (38.0%) (Coster et al., 2011). Building onto that research, Bedell et al. (2013) confirm the presented data and add that the differences between groups remain and that they change minimally, i.e. insignificantly after adjusting for the children's age and family income. Out of the ten activity types, parents of children with disabilities have expressed their desire for a change of participation in 62.7% of the community-based activities, statistically higher than parents of children from the typical population did (38.0%), yet with the low effect size ($\eta^2_p = 0.15$). Here, the results of our research (35.8%, Table 6) are comparable to the results reported by Bedell et al. (2013) when it comes to the group of families with children with typical development. However, the overall satisfaction of parents of children with cerebral palsy from our research is somewhat lower than in parents of children with a broad range of disabilities, taking into account that they expressed their desire for a change in a greater number of activities (72.6% versus 62.7%).

In addition to the previously mentioned difference in the average age and age range of the children, such result may be a consequence of numerous other differences. Heterogeneity of samples according to the type and severity of disability and socioeconomic and cultural differences are some of them (research has been undertaken in the territories of the United States of America and Canada). The fact is that standards and expectations of parents for their child's participation vary in line with actual environments and specific activities and situations (Bedell et al., 2011), which additionally emphasizes the need to take into account the subjective dimension of participation during the assessment thereof and development of an intervention plan.

When participation in individual community-based activities was explored, the obtained results showed that more parents of children with cerebral palsy desired change across all items compared with parents of children with typical development (Table S7, Supplementary data), similar to the findings from previous research studies (Bedell et al.,

2013; Coster et al., 2011). Descriptively, the greatest percentage of parents of children with cerebral palsy from our research have expressed a desire for change in participation in activities in the domain of organised and unstructured physical activities, like participation in sports teams or schools, such as basketball, fencing, horseback riding or swimming, hiking, ball throwing, and cycling. Many parents have also expressed a desire for change in the participation of their children with cerebral palsy in community events (shows, concerts, going for walks) and socialising with other children (spontaneous gatherings outside home or school). Some authors have reported that the changes parents desire the most are those related to involvement in the community events (Radulović et al., 2014). Strategies used by parents to promote the participation of youth with physical disabilities focused primarily on their child's immediate physical environment (Killeen et al., 2019). Others have reported that children with disabilities prioritize entirely different activities than their parents. Specifically, children have selected the activities that they have been somewhat to very involved in, and their parents have selected the activities they thought their children have been less involved in (Liao et al., 2019). This finding has led the authors to the conclusion that children with disabilities have a unique view of participation, which is why individualized support programs and plans are a priority (Liao et al., 2019).

It seems like the finding that the highest levels of overall participation at home were confirmed primarily in passive, less demanding, and sedentary activities repeats here (Milićević, 2020). Therefore, the finding that more parents of children with cerebral palsy desired change across all items compared with parents of children with typical development might be considered expected, but also encouraging. This may indicate that parents have noticed the importance of engagement in the activities outside the home since they are useful for functional, motor and health status of their child in many ways. Apart from that, the results demonstrate that parents emphasize that a change is also needed in the social aspect of the everyday life of their child with cerebral palsy. Socialising with other children within the community, attending various cultural and arts events and spontaneously socialising are some of the ways to establish friendly relations and expand one's network of friends; among other things, such situations demand social interaction and communication and provide an opportunity for the children to adopt social skills. All of the above has been recognised as participation benefit (Bart & Rosenberg, 2011; Heah et al., 2007; Imms, 2020; King et al., 2003; Nedović et al., 2012; Simeonsson et al., 2001).

Contrary to above, the highest percentage of our parents of children with typical development express their desire for a change in activities in the domains of classes and courses, such as music, art, foreign language, and computer lessons, as well as for changes in engagement in organisations, groups, clubs and volunteer activities (Table S7, Supplementary data). In other words, the parents from this group primarily stress the need for their children's additional education and their organised engagement in the social life of the community. The emphasis on unstructured physical activities comes only after these structured and organised ones. This finding is understandable when one takes into consideration that parents of children with typical development are least satisfied with their children's participation in sedentary and passive activities within their home

setting, such as playing computer and video games, watching TV, videos and DVDs, and doing household chores (Milićević, 2020) and that increased physical and sports engagement is a way to prevent long-term negative effects of everyday physical inactivity and dominant sedentary activities on a child's health (Maher et al., 2007).

Statistically, differences in the change desired in relation to the type of activities between two groups are particularly evident in the domain of socialising with other children ($\varphi = -0.58$), organised physical activities ($\varphi = -0.49$) and unstructured physical activities ($\varphi = -0.45$; Table S7, Supplementary data). More specifically, parents of children with cerebral palsy expressed a desire for greater involvement of their children in neighbourhood outings than parents of children with typical development did (Figure 13). The same trend was confirmed in the type of change desired in various community events, and organized physical activities (Figures 14 and 15). This comparison demonstrates the essence of the differences between the parental perspectives on needed changes, as a subjective dimension, or characteristic, of participation in the community environment. Parents of children with cerebral palsy from our research are least satisfied with their children's participation in organised physical activities and socialising with other children, including attendance of shows, concerts or sports events; in other words, they have noticed and distinguished the health-related, functional, motor and social aspects and benefits of the community activities.

Taking into consideration all ten types of activities, the mentioned three domains are not among the top priorities in terms of change desired for parents of children with typical development. Similarly, parents of the children with typical development are least satisfied with their children's participation in the work of organisations, groups, clubs, or volunteer activities and extracurricular classes or courses, i.e. their additional educational and social engagement. Those activities, however, have been ranked among the last ones according to the data about the satisfaction level of parents of children with cerebral palsy (Figure 12; Table S7, Supplementary data).

Compared to our results, parents of children with a broad range of disabilities have expressed in a much smaller percentage their desire for a change of participation in organised physical activities (Bedell et al., 2013, p. 319). They are more satisfied with participation when it comes to neighbourhood outings (e.g. shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore) and overnight visits or trips than the parents of children with cerebral palsy from our research. This difference may be described as expected since the aforementioned research mostly notes higher diversity, frequency, and level of involvement of children with disabilities in those domains. Also, 19.1% of them had a motor disorder or physical impairment as their primary disability, i.e. 35.5% of them had a motor disorder as an accompanying disorder, while in our research all children had the cerebral palsy diagnosis. When it comes to children from the typical population, descriptively, the greatest differences are in religious or spiritual gatherings and activities; a significantly higher percentage of parents of children with disabilities have expressed their desire for change even though these children participate, in a higher percentage and more often, in these activities but with a lower level of involvement compared to children with typical development from our research. Everyday life tempo, different dynamics of socialising

with peers, cultural but also socioeconomic differences are all potential explanations of the observed trend in differences; a more detailed review of these problems requires a qualitative research approach.

Community environment structure

The second research question referred to the differences in the structure of environmental factors relevant to community participation between the group of children with cerebral palsy and the group of children with typical development. It was hypothesized that there were differences in the structure of environmental factors relevant to community participation between the group of children with cerebral palsy and the group of children with typical development.

According to the results, there are statistically more barriers ($\eta^2_p = 0.21$) and fewer facilitators ($\eta^2_p = 0.04$) in the community environment in the group of children with cerebral palsy than the group with children with typical development (Table 7). Further, a smaller percentage of parents of children with cerebral palsy have perceived the community environment as helpful ($\eta^2_p = 0.31$) and resources as available and/or adequate ($\eta^2_p = 0.28$) to support their child's participation in the community. Overall, environmental supportiveness is lower in the group of children with cerebral palsy, indicating that community environment provides less support (less helpful/resources) for the participation of children from this population ($\eta^2_p = 0.39$). These findings are consistent with the previous studies (Bedell et al., 2013; Coster et al., 2011).

Differences in the extent of barriers and supports

When the differences were examined in more detail, the following trends in the distribution of results were identified, i.e. characteristics of participation. Every other child with cerebral palsy encounters at least twice as many barriers in the community compared to peers with typical development (Figure 23). The differences, on the other hand, are less pronounced when it comes to facilitators (Figure 24). While all environmental items help support community participation of every other child with typical development, the same could be said for only 9% of children with cerebral palsy (Figure 25). Furthermore, all environmental resources are available/adequate for every third child with typical development and less than 2% of children with cerebral palsy (Figure 26). Overall, 100% environmental support is provided to 20% of children with typical development and less than 1% of their peers with cerebral palsy (Figure 27).

To understand better the differences in the extent of barriers and supports, all nine domains of community environment structure were compared between two groups (Table S9, S10 and S11, Supplementary data). Barriers with the largest effect size were noted in the physical demands of typical activities, such as strength, endurance, and coordination ($\phi = -0.53$; Table S9, Supplementary data). In addition to the physical layout

or amount of space outside and inside buildings, the following items were singled out as barriers with moderate effect size: cognitive demands of typical activities (e.g., concentration, attention, problem solving), sensory qualities of community settings (e.g., noise, crowds, lighting) and outside weather conditions (ϕ ranging from -0.31 to -0.45).

As explained, motor disorder dominates in the clinical picture of cerebral palsy, accompanied by a group of heterogeneous symptoms (Rosenbaum et al., 2007). This complexity of cerebral palsy consequences is expressed in the interactions with environmental factors outside the home setting, as already adapted to the needs of a child with cerebral palsy to a certain extent, as shown by previous research indicating partial adaptation of the home structure (Milićević, 2017). However, in this case, there is interaction with environmental factors from the community setting, such as distance from shops, presence of pavements or lack thereof, accessibility of ramps or elevators, noise, crowds, light, temperature, and climate, but also concentration, attention, problem-solving, strength, endurance and coordination. According to the parents, group differences were particularly evident in the physical and cognitive demands of typical activity, the physical layout and sensory qualities of community settings (Figure 28), which may be the explanation of the stated finding.

The social aspect of the environmental factor structure should be outlined, as well. Compared to parents of children with typical development, more parents of children with cerebral palsy have evaluated the social demands of typical activities ($\phi = -0.27$) and the child's relationships with peers ($\phi = -0.24$) as barriers to community participation (Table S9, Supplementary data). Differences in attitudes and actions of other community members towards the child and safety of the community (e.g., traffic, crime, violence) have not reached statistical significance. The presented distribution is partially comparable with the results published in the comparative study of children with typical development and children with a broad range of disabilities aged between five and 17. Bedell et al. (2013) reported that a comparable percentage of parents of children with disabilities had assessed physical, sensory, and cognitive elements of the community environment as barriers. Descriptively, the results diverge in the social aspect of the community environment. More precisely, social demands of typical community activities, the relationship with peers and the attitudes and actions of other people are factors rated as barriers more often than in our research (46%, 29% and 21% versus 17%, 12%, and 6%, respectively). The same trend was noted after a comparison with the results presented by Chen et al. (2012), also. One more research should be mentioned (Radulović et al., 2014), with different distribution when it comes to the physical layout and amount of space outside and inside buildings, the attitudes and actions of other community members and the child's relationships with peers as barriers (39%, 52% and 49% versus 35%, 6% and 12%, respectively). Moreover, children with cerebral palsy whose local environment had more facilities had better social participation, and attitudes of strangers and staff in public places, lack of suitable transport and the presence of stairs were confirmed as barriers (Welsh et al., 2006). As presented in a prospective cohort study on childhood predictors of participation of young adults with cerebral palsy in domestic life and interpersonal relationships, focusing on social skills and communication

during childhood rehabilitation may optimize future participation in interpersonal relationships (van Gorp, E. Roebroek, et al., 2019)

When it comes to facilitators or supports, there was no statistically significant difference in parental ratings (Table S10, Supplementary data). In other words, environmental community factors were rated equally as factors that usually helped the child to participate in activities in the community (Figure 29), which is consistent with the previous research (Bedell et al., 2013). However, it should be emphasized that in our research, a higher percentage of parents from both groups assessed all factors as facilitating. There were 7% to 51% of parents of children with cerebral palsy and 13% to 46% of parents of children with typical development rated factors as facilitators. Bedell et al. (2013, p. 320) reported a range of 2% to 18% for parents of children with disabilities and 3% to 24% of parents of children from the typical population.

This finding can be described as positive and encouraging since it shows where the opportunities for improvement or optimization of participation are. It can also be considered supportive for improvement of the quality of life, having in mind that the level of participation has a limited effect on the quality of life of the children with cerebral palsy in age 8–12 years (Mc Manus et al., 2008). In our research, more parents of children with cerebral palsy have stated that social demands of typical community activities, the relationship of their child with peers and the attitudes and actions of other community members are the factors that made their child's participation harder.

Besides, it is noteworthy that more than half (50.9%) of parents of children with cerebral palsy have stated that the attitudes and actions of other community members towards their child usually helped their child to participate in the community. Similarly, parents have also stated the same for the relationship of their child with their peers (40.9%). Available research report about the descriptively lower percentage of parents of children with disabilities aged between five and 17 years, who described the same environmental factors as facilitators (Bedell et al., 2013; Chen et al., 2012). Most often, the social environment support (frequently expressed through attitudes) and accessibility without architectural barriers are indicated as facilitating environmental factors. Forsyth et al. (2007) noted that participation of young children with severe disabilities is affected to similar extents by intrinsic impairment and environmental factors: support, physical accessibility and transport. Previously, Lawlor et al. (2006) identified the following environmental factors: transport and mobility, support by and to parents and attitudes of individuals and institutions towards children. Law et al. (2007) described attitudes and social support as important in recreational, community, and school participation for children with physical disabilities.

Next, the differences between the groups are more noticeable when considering the distribution of the “not an issue” responses (Table S11, Supplementary data). Significantly more parents of children with typical development assessed environmental factors as factors not important for their child to participate in community-based activities, or as factors that did not affect participation (Figure 30). When it comes to this quality of environmental features, the greatest difference is in the physical demands of typical community activities ($\phi = 0.55$). An exception, i.e. factor without the statistical

significance of the difference between the groups, is the safety of the community (e.g., traffic, crime, violence). The obtained distribution is comparable with the finding from the previous research (Bedell et al., 2013). However, lower percentages of parents from both groups were found in our study.

Except for external weather conditions, the attitudes and actions of others, the child's relationship with peers and social demands of activities are the environmental features that the smallest number of parents of children with cerebral palsy from our research assessed as barriers and vice versa, most of them rated these factors as facilitators of community participation. The physical and cognitive demands of typical activities, in addition to physical, spatial, and architectural characteristics of the surrounding, are usually described as barriers and obstacles. The results are consistent with the results of similar studies and confirm the importance of the role of these factors (W. Chen et al., 2012; Law et al., 2007; Lawlor et al., 2006; Welsh et al., 2006). Some of the barriers reported in a study of the physical, social and attitudinal environments influencing the participation are staring or patronising attitudes of strangers, whereas supervision from parents in mobilization and leisure activities and attitude of family in promoting child's independence were facilitators (Lawlor et al., 2006).

Specialized equipment, e.g. electric wheelchairs, walking frames and adapted home environments facilitate home participation (Lawlor et al., 2006). Having in mind the previously presented analysis of the structure of the home environment (Milićević, 2017, 2020), the finding related to the community environment may be explained similarly. Environmental factors per se, as reported by parents of children with cerebral palsy, are more often either barriers or facilitators for their child's community participation. In contrast, when it comes to children with typical development, parents more often believe that environmental factors are either not an issue or facilitating their child's community participation. Reducing the number of barriers, i.e. elimination of aggravating influence of environmental factors with enforcing their facilitating role, is one of the ways to overcome the gap and harmonize support of the environment and participation potential of children from this population. It is necessary to recognize the importance and use the possibility of relatively high representation of assessment of environmental factors related to social demands of the activities, relations with peers and attitudes and actions of other people as facilitators, and relatively lower representation of assessment of these factors as barriers to community participation.

Differences in the availability and adequacy of resources

As stated by parents of children with cerebral palsy, resources evaluated as usually not available and/or adequate to support their child's community participation in the highest percentage in comparison to parents of children with typical development are access to public transportation and money ($\varphi = -0.47$, both), equipment and supplies ($\varphi = -0.45$), and programmes and services ($\varphi = -0.36$). These differences were statistically significant with a moderate effect size. At the same time, parents of children with cerebral palsy reported in the lowest percentage (6.4%) and comparable to the parents of children with

typical development (4.1%) that family did not have enough time to support their child's participation within the community (Table S12, Supplementary data).

Barriers to public transportation have a direct effect on the ability of people with disabilities to engage fully into activities in their community (Bezyak et al., 2019). More problems using public transportation for community participation were detected in individuals with multiple disabilities, along with multiple disabilities with blindness or no useful vision, psychiatric disabilities or chronic health conditions (Bezyak et al., 2019). The finding that lack of information and financial support, as well as the unavailability of public transportation (Figure 31), are frequent barriers to community participation is consistent with previous studies describing environmental barriers specific to children with disabilities (Lawlor et al., 2006; Nedović et al., 2012; Radulović et al., 2014). A study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in northeast England has emphasized access barriers in public transport, and also the inadequacy of information, space for equipment and financial support to parents due to reduced earning capacity (Lawlor et al., 2006). When general community factors impacting participation at the children's earliest age were explored, transportation and parking are listed among supplies and information (Khetani, Cohn, et al., 2013). Therefore, parenting strategies to promote participation in community activities included getting information, safety and advocacy, such as preparing the speech and using disability discounts (Khetani et al., 2013). Lack of equipment, information and organization are identified as primary determinants of participation of children and youth with physical disabilities in the systematic review (Shikako-Thomas et al., 2008).

In addition to personal transportation, time is among the most available resources, as reported by parents of children with cerebral palsy (Figure 32). Differences between two groups have not been statistically confirmed when responses that the family does have enough time (55.5% to 62.6%) and available personal transportation (63.6% versus 56.1%) are taken into consideration. Parents of children with cerebral palsy have rated most of the other resources less frequently as available and/or adequate, except for programmes and services within the community. This outcome is expected and supported by a statistically significant difference with large effect size between two groups when it comes to evaluation of the need for both personal and public transportation. Previous studies have also confirmed that private transportation is a significant facilitator of community participation (Lawlor et al., 2006). Parents of children with cerebral palsy need extra time for community-based activities and extra time and planning for journey, as well (Lawlor et al., 2006). Physical distance and time constraints were also identified as barriers (Heah et al., 2007).

Bedell et al. (2013) presented a somewhat comparable structure in their study on community participation of school-age children with a broad range of disabilities in comparison to their peers without disabilities. First, there was no difference between two groups of children in the domain of personal transportation; compared to our results, descriptively, a smaller percentage of parents of children with disabilities stated that this resource was not available to them (2% versus 18% of parents of children with cerebral in our research). Similarly, while less than 1% of parents of children with cerebral

palsy in our study stated that they did not need personal transportation (Table S13, Supplementary data), 10% of parents of children with disabilities reported the same (Bedell et al., 2013). The second key difference was in the domain of public transportation. As reported by Bedell et al. (2013), parents of children with and without disabilities equally evaluated this resource as usually available and/or adequate (78% versus to 85%). In our research, significantly fewer parents of children with cerebral palsy than parents of children with typical development reported that access to public transportation was available and/or adequate (26% versus 57%; Figure 32). The third difference is notable in the distribution of responses to the question about the availability of time to support the child's participation in community-based activities. There were significant group differences in whether parents had or did not have enough time (Bedell et al., 2013). However, in our research, there were no significant differences between groups; parents of children equally had or did not have enough time (Figures 31 and 32). In different settings, time affects participation, but also on everyday life activities (Bedell et al., 2011; Heah et al., 2007).

Descriptively, the greatest dissimilarities in responses are in the availability of money, and the availability and adequacy of equipment. This comparison confirms that the same environmental factors within different settings may be perceived differently; their role is modifiable and variable depending on actual environments and different populations, making the theoretical construct of a child's participation more complex. The fact is that the sample structures from these two studies differ. Among other things, there are different distributions according to the level of education of the parents, family income, and type of community. In addition to culture and global socioeconomic differences, these distribution differences make a direct comparison between the findings harder.

Community participation and functional limitations of children with cerebral palsy

The third research question referred to the relationship between characteristics of participation and the features of a community environment and functional limitations of children with cerebral palsy. It was hypothesized that functional limitations of children with cerebral palsy were associated with the characteristics of community participation and features of the community environment.

Results have confirmed that certain characteristics of community participation of children with cerebral palsy are associated with their functional limitations (Table 8). Higher levels of functional limitations were associated with lower involvement in community-based activities, the lower frequency with more severe limitations of fine manual abilities, whereas intellectual functioning correlated with supports, environmental helpfulness and overall environmental supportiveness.

The number of community-based activities in which children with cerebral palsy were involved in, i.e. diversity of participation, correlated with the level of intellectual functioning. Next, the level of involvement was in small to moderate correlations with

gross motor and fine manual abilities (GMFCS and MACS level) and the level of intellectual functioning. In other words, more severe impairments of gross motor and fine manual abilities are associated with and a lower level of the actual involvement of children. Additionally, children with lower levels of intellectual functioning participated in fewer community activities. At the same time, there was no correlation between participation frequency and functional limitations of children with cerebral palsy.

Reduced participation diversity and intensity were noted in children with more severe functional limitations earlier (Imms et al., 2008, 2009; Longo et al., 2013; Majnemer, Shevell, Law, Birnbaum, et al., 2008; Orlin et al., 2010; Palisano, Orlin, et al., 2011; Vila-Nova et al., 2020). Restrictions encountered by adolescents and young adults with cerebral palsy aged 16 to 20 years in daily activities (mobility, self-care, nutrition) and social participation (taking responsibility, community living, leisure activities and employment) are mainly attributable to the severity of their gross motor functioning (Donkervoort et al., 2007). Functioning, activity, and participation of school-aged children with cerebral palsy, evaluated by ICF-CY checklist, significantly differed by their MACS level, while the functioning influenced both activities and participation (Lee et al., 2015). Cognitive function is a strong predictor of both diversity and frequency of participation in leisure activities in children with cerebral palsy aged 8 to 18 years in the metropolitan area of Lisbon and the South of Portugal (Vila-Nova et al., 2020).

Descriptively, children with the most severe forms of cerebral palsy, i.e. with gross motor and fine manual abilities classified as GMFCS IV/V or MACS IV/V, had less diverse community participation, especially in unstructured and organized physical activities and getting together with other children (Figures 34 and 35). A similar trend was found when the level of intellectual functioning was examined (Figure 36). Yet, there were only a few and not strong association. Both effect sizes and coefficients of Spearman's rank correlation are interpreted as moderate (Table S15 to S19, Supplementary data). It is necessary to have a closer look at this outcome.

Our finding could be interpreted as a reflection of a lack of variation in diversity and frequency of participation. This interpretation could further indicate that functional limitations of children with cerebral palsy are not directly limiting or reducing children's opportunities to participate. As explained, participation is an actual involvement and performance in specific life situations (Granlund et al., 2012). One of two essential elements of participation is attendance, which is characterized as 'being there' and measured as the frequency of attending and/or the diversity of activities (Imms, Adair, et al., 2016; Imms, 2020). However, diversity and frequency are related to the availability and access to everyday activities (Granlund et al., 2012). The consequences of the presence of cerebral palsy are visible in the dynamics of everyday family life as a lower frequency of family activities, that is, children with cerebral palsy experience less diverse family activities and have less frequent opportunities to be involved in a life situation (Milićević, 2016). Many family activities take place in a community setting, for example, outings, going on vacations or weekend, organized activities, outdoor activities. The finding is explained by the fact that the given activities are time-consuming and financially demanding and that it is necessary to provide resources, better availability of

information, transport, and wider social network, which was confirmed as unavailable/inadequate resources in our research (Figure 31).

Contrary to the above mentioned, but comparable with the findings obtained within home settings (Milićević, 2020), frequency of participation in the community did not correlate with functional limitations of children with cerebral palsy. The only two exceptions are organized physical activities, which correlated with fine manual abilities (Figure 37), classes and lessons, not school-sponsored, which correlated with intellectual functioning (Figure 38). Previous studies reported that better gross and/or fine motor abilities are most often related to a higher frequency of participation in home, extracurricular and community activities, mostly informal ones (Imms et al., 2009; Longo et al., 2013; Mc Manus et al., 2008; Michelsen et al., 2009; Orlin et al., 2010; Palisano et al., 2012; Palisano, Orlin, et al., 2011). Our findings partly overlap with the results presented by Imms et al. (2008). As reported, diversity and frequency of participation in formal and informal activities were similar for children in each GMFCS and MACS level, except for children with the most severe functional impairments, i.e. GMFCS V and MACS V. Similarly, Park and Kim (2015) reported statistically significant differences in frequency of participation between the levels I and V of gross motor functioning (GMFCS), fine manual abilities (MACS), but also communication abilities (CFCS; Hidecker et al., 2011). These dissimilarities may result from differences in participants' age, disability status, or distribution of functional limitations in gross and/or fine motor functions, including different research methodology.

Next, the relationship between the functional abilities of children with cerebral palsy and structure of environmental features in the community was explored (Table 8). Parents of children with cerebral palsy with more severe limitations in the intellectual functioning rated less environmental factors as supports and the environment as less helpful in supporting their child's participation. This finding shows that intellectual abilities are important for community participation and our results have previously confirmed their association with two of the three general characteristics of the participation (diversity and level of involvement; Table 8). Namely, when it comes to environmental features in the community, it may be concluded that the community is perceived as more helpful and supportive for those children with cerebral palsy whose intellectual functioning is higher. Bearing in mind that cerebral palsy is manifested by a motor disorder, the question arises why the motor abilities, gross or manual, are not related to the parental evaluation of the environmental factor structure. The fact that these correlations are not statistically significant first indicates the possibility that the parents of children with cerebral palsy describe in similar terms the environmental structure of the community they live in, regardless of the severity of cerebral palsy expressed through the severity of motor impairment. In support of this interpretation, other studies indicated a not very strong association between upper extremity function of children with cerebral palsy and participation in different life areas and with different dimensions of participation, especially parental satisfaction dimension (Pashmdarfard & Shervin Badv, 2019). Furthermore, evidence for improvement in activities and participation of children and adolescents with cerebral palsy after upper extremity surgery is limited (Louwers et al., 2019).

To explore this finding in more detail in our sample, subsequent analyses of the relationship between functional limitations and individual environmental factors were performed (Table S20, Supplementary data). Of the environmental factors, several statistically significant correlations with functional abilities were confirmed. According to the literature, parents describe environmental factors rather as barriers if the level of physical functioning of a child with a physical disability is lower, i.e. in those children with the most limited ability to perform daily tasks independently (Law et al., 2007). Recently, functioning of pre-school children with a disability or at high risk of having a disability was a predictor of the parents' perception of environmental barriers in the community setting and not with the child's frequency of participation in community activities (Guichard & Grande, 2019).

When it comes to the features of environmental helpfulness, only gross motor skills were related to the sensory qualities of community settings. This may indicate that greater impairment of gross motor functioning is associated with a tendency to assess this environmental quality as a barrier to community participation (Figure 42). The finding confirms that noise, crowds, and inadequate lighting make community participation additionally difficult for children and adolescents with cerebral palsy if their gross motor functioning is severely limited. Similarly, outside weather conditions were rated as harder for the child to participate in the community if the child had a more severe intellectual impairment (Figure 43). Features of the sensory profile of persons from this population are distinctive and connected with limitation in motor behaviour. Moreover, low reception of sensory stimuli and lower achievements in performing complex motor tasks are manifestations of difficulties in sensory processing (Potić, 2014). Therefore, the question remains whether there is a cumulative effect of these features on community participation. In some future research, it would be useful to examine this assumption in more detail, as well as the possibility of improving community participation by optimizing the combination of motor behaviour and sensory processing, through the modification of the sensory qualities of the environmental structure.

Statistically, two more correlations were confirmed as significant, i.e. between the level of intellectual functioning and both social and cognitive demands of typical community-based activities (Figure 43). This finding indicates that more severe levels of intellectual impairment are associated with more difficulties in concentration, attention, problem solving, communication and interacting with others, making it harder for children with cerebral palsy to get involved in activities. The finding that cognitive and social demands of community-based activities are more evaluated as barriers if intellectual functioning is lower is expected and in line with previous findings on the importance of communication abilities, as well (Batorowicz et al., 2014; Mei et al., 2015). In the mentioned study, it was shown that aspects of parents' own interactions with their child, unfamiliar people and settings, negative attitudes of others and children's frustration were key barriers to participation, while facilitators were support received from the child's family and school and getting together with other children (Mei et al., 2015). Diversity and frequency are influenced by the social environment and physical restrictions, including attitudes, transportation and physical barriers (Lawlor et al., 2006; McManus et al., 2006; Welsh et al., 2006). There are some indications that children with

cerebral palsy may depend upon additional support from their family or other members of the community to get involved into activities, but also they may require environmental adaptations (Lawlor et al., 2006; Vila-Nova et al., 2020). Our finding confirms the mentioned importance of communication abilities, problem-solving abilities, memory, and social interaction in the perception of the role of certain environmental features.

Subsequent analyses of the relationship between functional limitations and individual resources (Table S20, Supplementary data) have confirmed that severe gross motor and fine manual limitations were associated with unavailability and/or inadequacy of public transportation to access community activities (Figure 44). The finding suggests that the availability and adequacy of public transportation are related to independence that is related to mobility. Independence in activities occurred as one of the major themes in defining successful participation (Heah et al., 2007).

Study limitations and future research directions

Several limitations of our study should be mentioned.

The sample included a relatively small number of respondents. It was formed by the convenience sampling, and partially by snowballing, so groups are possibly biased. As highlighted, sampling has far-reaching implications. The convenience sampling strategy is lacking representatives of sociodemographic subgroups and provides insufficient power to detect sociodemographic group differences, among other things (Bornstein et al., 2013). Correspondingly, snowball sampling results include participants from the same geographical area with similar socioeconomic statuses or ethnic backgrounds, which might skew the results and have an impact on the subject of study (Emerson, 2015).

Next, no population-based cerebral palsy register is available in Serbia (Demeši Drljan, 2011; Milićević & Simeunović, 2020) and the accurate statistics on the number of children with cerebral palsy in Serbia and their functional characteristics is lacking. A wider range of sociodemographic factors could provide better representativeness of the sample in relation to the population of persons with cerebral palsy, both in terms of gender and age structure, and in terms of variability in the level of motor impairment and the presence of associated and accompanying disorders. For these reasons, replication of this study with larger samples and application of criteria of representativeness could provide more assurance and generalizability of the findings.

Data on the functional characteristics of children with cerebral palsy were collected after parents or caregivers had accepted to participate in this study. Therefore, it is not known whether there were statistically significant differences in comparison to those children with cerebral palsy whose parents or caregivers refused the invitation to participate. The only thing examined, there were no statistically significant differences related to gender ($p = 0.263$, $\phi = -0.06$) and age ($p = 0.100$, $\phi = 0.09$) of children whose parents or

caregivers accepted or refused our invitation to participate. Moreover, no data on the reasons for refusing to participate in this study were collected from institutions, parents and caregivers (Milićević & Nedović, 2018).

Furthermore, the preferences of parents and children, when it comes to the choice of activities, were not taken into account, nor were the level of enjoyment of children with participation in certain types of activities. At the same time, possible differences in evaluation according to the characteristics of the family or parents (age, gender, level of education, marital status, employment, family income, place of residence) were not included in the analysis. Only children's gross motor, manual, and intellectual functioning were taken into consideration within analyses on the relationship between community participation characteristics and functional limitations of children with cerebral palsy. Previous research has shown that these factors affect different characteristics of participation of children with disabilities (Engel-Yeger et al., 2009; Khetani, Graham, et al., 2013; Law et al., 2006; Longo et al., 2013; Majnemer et al., 2010; Shikako-Thomas et al., 2015; Shikako-Thomas, Shevell, Lach, et al., 2013).

Finally, the findings were based on the data collected from parents only, therefore reflecting the parent's views of the child's participation. In one study, it was shown that children with disabilities perceived their participation different than their parents, and that they had selected entirely different items as their desire-to-change activities (Liao et al., 2019). Earlier, it was reported that parental perceptions are influenced by the burden of caregiving, among other things and that there is a disagreement between characteristics of assessment from children's and their parents' perspective (Khetani et al., 2009; Milićević & Klič, 2014).

CONCLUSION AND IMPLICATIONS

The overarching aim of this study was to examine the characteristics of community participation of children with cerebral palsy in comparison to their peers with typical development, the effect of the environment on this participation and the association with functional limitations of children with cerebral palsy, from the perspective of parents. To our knowledge, this is the first attempt to explore community participation of children with cerebral palsy comprehensively with respect to a specific setting.

Community participation was operationalized as a child's involvement in activities that were performed outside the home environments, including the neighbourhood, extracurricular activities at school environment, within and beyond the community where the child lived (Kang, 2010, p. 29). The overarching aim was achieved by analysing the diversity of activities in the community environment, frequency of involvement in activities of a certain type, and the level of involvement in the given activities. In addition, the level of parent's satisfaction with the child's current participation and the type of change desired were explored. The structure of environmental factors was related to facilitators (or supports) and barriers specific to the community, parent's perception of the availability of environmental resources, how helpful the environment was and how it supported the child's participation.

On community participation

The first research question was to examine whether there were differences in characteristics of participation in community-based activities between the group of children with cerebral palsy and the group of children with typical development. The first hypothesis was set that characteristics of participation in community-based activities differed between the group of children with cerebral palsy and the group of children with typical development.

The results of our study show that the overall participation of children with cerebral palsy in the community is lower compared to the participation of children with typical development. Children with cerebral palsy participate in fewer activities, less frequently and are involved to a lesser extent. Differences are also evident at the level of individual activity types.

Activities in which the lowest percentage of children with cerebral palsy participate are mostly organized, formal, structured and physically and/or cognitively demanding (foreign language classes, sports classes, recreational activities, music, art or computer classes, volunteering, involvement in organizations, groups or clubs, paid work, going to religious gatherings). They participate more in activities that are rather spontaneous, more accessible in the immediate setting and take place nearby (neighbourhood outings,

going to a store or shopping centre, going to a cinema, attending a play, hanging out, informal gatherings outside of the home or school).

Excluding activities in which they never participate, children with cerebral palsy engage less frequently in four of the ten types of activities with a difference of moderate effect size. The key difference in community participation characteristics between two groups of children is in the child's level of involvement. Comparable to home participation, characteristics of community participation should not be considered separately when analysing participation in a given environment (Hammel et al., 2008; Imms, 2020; Imms et al., 2016, 2017; Milićević, 2020). This refers to information on whether a child with cerebral palsy participates in certain type of activity or not, and if so, how often and to what extent is involved.

Therefore, information on the frequency of participation should not be the only indicator and/or measure of the success of involvement in life situations and the effectiveness of implemented support programs. To understand participation fully and more comprehensively, all its dimensions need to be taken into consideration.

More parents of children with cerebral palsy reported that they would like to see their child's community participation change. Higher frequency, greater involvement and a broader variety of activities are the desired types of change. Based on the distribution of responses and statistical analysis of differences between two groups, it can be concluded that parents see the importance of engaging in those activities outside the home environment that are beneficial for functional, motor and health status of the child (organized and unstructured physical activities), in activities involving social interaction and communication and those that provide children with the opportunity to acquire social skills (socializing with other children in the community).

Based on the presented findings, it can be concluded that the characteristics of participation, including overall parental satisfaction with the child's current participation, differ between the group of children with cerebral palsy and the group of children of typical development, confirming the first hypothesis.

On community environment

The second research question was to examine whether there were differences in the structure of environmental factors relevant to community participation between the group of children with cerebral palsy and the group of children with typical development. The second hypothesis was set that structures of environmental factors relevant to community participation differed between the group of children with cerebral palsy and the group of children with typical development.

By comparing the structures of environmental factors, the results of our study indicate more barriers and fewer facilitators in the group of children with cerebral palsy. Additionally, the environment is overall less supportive, environmental factors are rated less often as helpful in the child's participation, and community resources are less available and/or adequate.

Areas identified as the greatest barriers for children with cerebral palsy include physical (strength, endurance, coordination) and cognitive demands of typical community-based activities (concentration, attention, problem-solving), as well as the physical layout of community settings or amount of space outside and inside buildings (distances to stores, presence of sidewalks, availability of ramps or elevators). On the other hand, the greatest supports include attitudes and actions of other members of the community towards the child, relationships with peers and social demands of typical community-based activities (communication, interacting with others). Although parents of children with cerebral palsy rate environmental factors as support less frequently than parents of children with typical development do, there are no significant group differences.

Most importantly, there is a high prevalence of those parents of children with cerebral palsy who assessed the factors of social demands of typical activities, the child's relationship with peers and the attitudes and actions of others as usually facilitating or supportive. The importance of this finding is in drawing attention to the potential that the setting of the community can have in facilitating, i.e. supporting the overall participation of children and adolescents with cerebral palsy.

When it comes to resources, public transportation, money, equipment or supplies, including assistive devices or technology, programs and services, such as inclusive sports programs and personal assistant are usually unavailable or inadequate.

In general, there is a lack of more adequate services in the community. The difference between two groups is in the readiness of that immediate setting to fulfil, through help, support and resources, its mediating role at the intersection between personal factors, on the one hand, and the outcome of participation, on the other. In addition to the finding of the comparable frequency of community participation, it can be concluded that a more accessible and adapted environment is an important prerequisite for improved and enhanced participation.

The importance of this finding is in detecting those environmental features whose facilitative role could be improved, but also in drawing attention to those barriers that could be removed or modified to enhance community participation of children and

adolescents with cerebral palsy. It has also been shown that the absence of barriers does not necessarily lead to participation that is more successful and that supporting factors and the availability of adequate resources are relevant for the outcome of community participation.

In other words, reducing the number of barriers, i.e. removing the aggravating influence of environmental factors while enforcing their facilitative role, is one of the ways to harmonize the support of the environment and enhance the participatory potential of children from this population. It is necessary to recognize the importance and use the possibility of relatively high representation of assessment of environmental factors related to social demands of the activities, relations with peers and attitudes and actions of other people as facilitators, and relatively lower representation of assessment of these factors as barriers to community participation.

Based on the presented findings, the structures of environmental factors relevant to community participation differ between the group of children with cerebral palsy and the group of children with typical development. It can be concluded that the second hypothesis has been confirmed.

On relationship between community participation characteristics and functional limitations of children with cerebral palsy

The third research question was to examine if characteristics of community participation and the features of the community environment were related to the functional limitations of children with cerebral palsy. The third hypothesis was set that functional limitations of children with cerebral palsy were associated with the characteristics of community participation and features of the community environment.

Functional limitations (gross motor, fine manual and intellectual functioning) are associated with the lower involvement in community-based activities. Only more severe limitations of fine manual abilities are associated with lower participation frequency. At the same time, more severe levels of intellectual disability are associated with less diverse community-based activities and/or lower involvement levels. Activities affected by functional limitations are unstructured and organized physical activities, getting together with other children, and to a lesser extent, community events, neighbourhood outings, overnight visits or trips and extracurricular classes and lessons.

More severe levels of intellectual disability are associated with social and cognitive demands of typical activities. In addition, outside weather conditions are rated more often as harder for the child to participate in the community.

More severe gross motor and fine manual limitations are associated with unavailable and/or inadequate access to public transportation. The availability of public transportation to access activities, availability and/or adequacy of equipment or supplies in community and the attitudes and actions of other community members are the most influential barriers.

Overall, additional attention should be paid to children with cerebral palsy whose intellectual functioning is more limited. The results show that these children are at increased risk of fewer supporting factors and collectively less support and help from the environment. More specifically, this risk is manifested through the cognitive and social demands of typical community-based activities. Motor impairment and mobility limitations are reflected in the interaction with public transportation, but also with the sensory qualities of the community environment.

Based on the presented findings, functional limitations of children with cerebral palsy are associated with the characteristics of community participation and the features of the community environment. It can be concluded that the third hypothesis has been confirmed.

Implications for special education and rehabilitation

- (1) All characteristics of participation are equally important in creating a participation profile of a child with cerebral palsy.
- (2) Compared to children with typical development, special attention should be paid to differences in diversity and type of community-based activity, as well as the level of involvement.
- (3) Parent-reported need for change may assist professionals in the design of a context that improves community participation of children with cerebral palsy.
- (4) In the field of special education and rehabilitation, professionals should take a more active role in arranging, accommodating and/or modifying the logistics of the child's desired activities, following the participation-based approach.
- (5) The child's relationships with peers, social demands of typical community-based activities and attitudes and actions of other members of the community towards the child, as supportive factors, should be considered by professionals to promote overall community participation.
- (6) There is a need to develop strategies for a more accessible and adapted environment in order to optimize participation outcomes in community-based activities, as an early entry point of intervention, in the process of special education and rehabilitation.
- (7) Differences identified in this study may serve as basis for treatment planning and its periodic monitoring.
- (8) Additional attention should be paid to children with cerebral palsy and associated disorders due to increased risk of less supportive and less helpful environment and less available and/or adequate community resources.
- (9) The profile of functional abilities of children with cerebral palsy interacts with the structure of environmental features, which is manifested through cognitive and social demands of typical community-based activities, unavailability or inadequacy of resources, but also through the sensory qualities of the community environment.

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Supplementary data

Table S1. PEM-CY community participation summary scores: unadjusted means and adjusted means for family income category

Community participation summary scores	Group	Unadjusted	Adjusted for family income			Differences
		M (SD)	M	SE	95% CI	
Participates ever, %	CP	50.36 (20.36)	52.04	1.79	[47.39, 56.70]	1.68
	TD	74.56 (15.11)	73.08	1.67	[68.75, 77.41]	-1.48
Participation frequency	CP	4.20 (1.07)	4.20	0.10	[3.95, 4.44]	0.00
	TD	4.83 (0.76)	4.84	0.09	[4.61, 5.06]	0.01
Level of involvement	CP	3.16 (1.07)	3.20	0.08	[2.97, 3.42]	0.04
	TD	4.63 (.53)	4.60	0.08	[4.40, 4.80]	-0.03
Desire for change, %	CP	72.55 (23.12)	71.57	2.61	[64.78, 78.35]	-0.98
	TD	35.84 (27.57)	36.70	2.43	[30.39, 43.02]	0.86

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; SE = standard error; CI = confidence interval in format [lower limit, upper limit]; Differences = differences between adjusted (controlling for family income) and unadjusted means.

Table S2. Group differences in PEM-CY community participation items scores: diversity in relation to the type of activities

Participation items (activity types)	Participates ever, n (%) [†]			
	CP	TD	p	φ
1. Neighbourhood outings	100 (90.91)	123 (98.40)	0.021	0.17
2. Community events	86 (78.18)	123 (98.40)	< 0.001	0.32
3. Organized physical activities	48 (43.64)	111 (88.80)	< 0.001	0.48
4. Unstructured physical activities	72 (65.45)	123 (98.40)	< 0.001	0.44
5. Classes and lessons (not school-sponsored)	30 (27.27)	90 (72.00)	< 0.001	0.45
6. Organizations, groups, clubs...	19 (17.27)	60 (48.00)	< 0.001	0.32
7. Religious or spiritual gatherings and activities	52 (47.27)	50 (40.00)	0.322	-0.07
8. Getting together with other children	86 (78.18)	122 (97.60)	< 0.001	0.30
9. Working for pay	2 (1.82)	22 (17.60)	< 0.001	0.26
10. Overnight visits or trips	59 (53.64)	108 (86.40)	< 0.001	0.36

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development.

Significant p values are shown in bold. Effect sizes (φ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.005$).

Table S3. *Group differences in PEM-CY community participation items scores: frequency in relation to the type of activities*

Participation items (activity types)	Frequency, <i>M</i> (<i>SD</i>) [†]			
	CP	TD	<i>p</i>	η^2_p
1. Neighbourhood outings	5.42 (1.49)	5.84 (1.12)	0.022	0.02
2. Community events	3.87 (1.75)	4.89 (1.41)	< 0.001	0.09
3. Organized physical activities	4.33 (2.04)	5.50 (1.45)	0.001	0.07
4. Unstructured physical activities	5.12 (1.56)	5.95 (0.97)	0.001	0.06
5. Classes and lessons (not school-sponsored)	4.47 (1.94)	4.99 (1.67)	0.193	0.01
6. Organizations, groups, clubs...	3.00 (1.53)	3.17 (2.00)	0.649	0.00
7. Religious or spiritual gatherings and activities	3.13 (1.79)	3.46 (1.64)	0.050	0.04
8. Getting together with other children	4.55 (1.91)	5.91 (1.29)	< 0.001	0.15
9. Working for pay ^a	3.50 (3.54)	4.41 (2.06)	/	/
10. Overnight visits or trips	2.00 (1.36)	2.19 (1.43)	0.725	0.00

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; η^2_p = partial eta squares (effect sizes) are rounded to two decimal points (small = 0.01–0.05; moderate = 0.06–0.13; large \geq 0.14).

Significant *p* values are shown in bold.

^a No comparisons were conducted due to the small subsample sizes (CP: *n* = 2, TD: *n* = 22).

[†] Based on analysis of covariance (ANCOVA) adjusting for family income category (Bonferroni adjustment of the significance level was set at *p* < 0.005).

Table S4. *Frequency of participation in relation to the type of community-based activities: unadjusted means and adjusted means for family income category*

Participation items (activity types)	Group	Unadjusted	Adjusted for family income			Differences
		<i>M</i> (<i>SD</i>)	<i>M</i>	<i>SE</i>	95% CI	
1. Neighbourhood outings	CP	5.42 (1.49)	5.40	0.14	[5.13, 5.67]	-0.02
	TD	5.84 (1.12)	5.85	0.12	[5.61, 6.10]	0.01
2. Community events	CP	3.87 (1.75)	3.83	0.18	[3.48, 4.18]	-0.04
	TD	4.89 (1.41)	4.92	0.15	[4.63, 5.21]	0.03
3. Organized physical activities	CP	4.33 (2.04)	4.44	0.25	[3.94, 4.93]	0.11
	TD	5.50 (1.45)	5.46	0.16	[5.14, 5.77]	-0.04
4. Unstructured physical activities	CP	5.12 (1.56)	5.20	0.15	[4.90, 5.50]	0.08
	TD	5.95 (0.97)	5.91	0.11	[5.68, 6.13]	-0.04
5. Classes and lessons (not school-sponsored)	CP	4.47 (1.94)	4.48	0.33	[3.84, 5.13]	0.01
	TD	4.99 (1.67)	4.98	0.19	[4.61, 5.35]	-0.01
6. Organizations, groups, clubs...	CP	3.00 (1.53)	2.92	0.49	[1.94, 3.90]	-0.08
	TD	3.17 (2.00)	3.19	0.26	[2.68, 3.70]	0.02
7. Religious or spiritual gatherings and activities	CP	3.13 (1.79)	2.94	0.24	[2.45, 3.42]	-0.19
	TD	3.46 (1.64)	3.67	0.25	[3.17, 4.16]	0.21
8. Getting together with other children	CP	4.55 (1.91)	4.46	0.18	[4.10, 4.82]	-0.09
	TD	5.91 (1.29)	5.97	0.15	[5.67, 6.27]	0.06
9. Working for pay ^a	CP	3.50 (3.54)	/	/	/	/
	TD	4.41 (2.06)	/	/	/	/
10. Overnight visits or trips	CP	2.00 (1.36)	2.07	0.20	[1.67, 2.47]	0.07
	TD	2.19 (1.43)	2.16	0.14	[1.88, 2.44]	-0.03

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; *SE* = standard error; CI = confidence interval in format [lower limit, upper limit]; Differences = differences between adjusted (controlling for family income) and unadjusted means.

^a No comparisons were conducted due to the small subsample sizes (CP: *n* = 2, TD: *n* = 22).

Table S5. Level of involvement in relation to the type of community-based activities: unadjusted means and adjusted means for family income category

Participation items (activity types)	Group	Unadjusted		Adjusted for family income			Differences
		M (SD)	M	SE	95% CI		
1. Neighbourhood outings	CP	3.39 (1.33)	3.43	0.12	[3.10, 3.76]	0.04	
	TD	4.60 (0.86)	4.57	0.10	[4.27, 4.86]	-0.03	
2. Community events	CP	3.19 (1.43)	3.16	0.12	[2.81, 3.50]	-0.03	
	TD	4.74 (0.69)	4.76	0.10	[4.48, 5.04]	0.02	
3. Organized physical activities	CP	3.54 (1.47)	3.64	0.14	[3.23, 4.05]	0.10	
	TD	4.78 (0.62)	4.74	0.09	[4.48, 5.00]	-0.04	
4. Unstructured physical activities	CP	3.50 (1.41)	3.51	0.12	[3.17, 3.85]	0.01	
	TD	4.84 (0.49)	4.83	0.09	[4.58, 5.08]	-0.01	
5. Classes and lessons (not school-sponsored)	CP	2.93 (1.64)	2.98	0.22	[2.33, 3.62]	0.05	
	TD	4.51 (1.01)	4.50	0.13	[4.13, 4.86]	0.01	
6. Organizations, groups, clubs...	CP	2.58 (1.30)	2.55	0.31	[1.67, 3.43]	-0.03	
	TD	4.19 (1.14)	4.20	0.16	[3.73, 4.66]	0.01	
7. Religious or spiritual gatherings and activities	CP	2.88 (1.57)	2.86	0.21	[2.25, 3.46]	-0.02	
	TD	3.92 (1.28)	3.95	0.21	[3.33, 4.56]	0.03	
8. Getting together with other children	CP	3.35 (1.38)	3.36	0.12	[3.02, 3.69]	0.01	
	TD	4.85 (0.63)	4.85	0.10	[4.57, 5.12]	0.00	
9. Working for pay ^a	CP	1.00 (0.00)	/	/	/	/	
	TD	4.40 (1.10)	/	/	/	/	
10. Overnight visits or trips	CP	3.57 (1.39)	3.71	0.16	[3.26, 4.16]	0.14	
	TD	4.65 (0.92)	4.57	0.11	[4.25, 4.89]	-0.08	

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; SE = standard error; CI = confidence interval in format [lower limit, upper limit]; Differences = differences between adjusted (controlling for family income) and unadjusted means.

^aNo comparisons were conducted due to the small subsample size (CP: $n = 2$, TD: $n = 22$).

Table S6. Group differences in PEM-CY community participation items scores: level of involvement in relation to the type of activities

Participation items (activity types)	Level of involvement, M (SD) [†]			
	CP	TD	p	η^2_p
1. Neighbourhood outings	3.39 (1.33)	4.60 (0.86)	< 0.001	0.18
2. Community events	3.19 (1.43)	4.74 (0.69)	< 0.001	0.32
3. Organized physical activities	3.54 (1.47)	4.78 (0.62)	< 0.001	0.20
4. Unstructured physical activities	3.50 (1.41)	4.84 (0.49)	< 0.001	0.28
5. Classes and lessons (not school-sponsored)	2.93 (1.64)	4.51 (1.01)	< 0.001	0.23
6. Organizations, groups, clubs...	2.58 (1.30)	4.19 (1.14)	< 0.001	0.22
7. Religious or spiritual gatherings and activities	2.88 (1.57)	3.92 (1.28)	0.001	0.11
8. Getting together with other children	3.35 (1.38)	4.85 (0.63)	< 0.001	0.30
9. Working for pay ^a	1.00 (0.00)	4.40 (1.10)	/	/
10. Overnight visits or trips	3.57 (1.39)	4.65 (0.92)	< 0.001	0.10

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; η^2_p = partial eta squares (effect sizes) are rounded to two decimal points (small = 0.01–0.05; moderate = 0.06–0.13; large ≥ 0.14).

Significant p values are shown in bold.

^aNo comparisons were conducted due to the small subsample sizes (CP: $n = 2$, TD: $n = 22$).

[†]Based on analysis of covariance (ANCOVA) adjusting for family income category (Bonferroni adjustment of the significance level was set at $p < 0.005$).

Table S7. Group differences in PEM-CY community participation items scores: change desired in relation to the type of activities

Participation items (activity types)	Desires change, n (%) [†]			
	CP	TD	p	φ
1. Neighbourhood outings	83 (75.45)	45 (36.00)	< 0.001	-0.40
2. Community events	92 (83.64)	55 (44.00)	< 0.001	-0.41
3. Organized physical activities	94 (85.45)	46 (36.80)	< 0.001	-0.49
4. Unstructured physical activities	93 (84.55)	51 (40.80)	< 0.001	-0.45
5. Classes and lessons (not school-sponsored)	81 (73.64)	63 (50.40)	< 0.001	-0.24
6. Organizations, groups, clubs...	69 (62.73)	36 (50.40)	0.077	-0.12
7. Religious or spiritual gatherings and activities	55 (50.00)	21 (16.80)	< 0.001	-0.35
8. Getting together with other children	93 (84.55)	33 (26.40)	< 0.001	-0.58
9. Working for pay	51 (46.36)	33 (26.40)	0.002	-0.21
10. Overnight visits or trips	87 (79.09)	38 (30.40)	< 0.001	-0.49

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development.

Significant p values are shown in bold. Effect sizes (φ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.005$).

Table S8. PEM-CY community environment summary scores: unadjusted means and adjusted means for family income category

Community environment summary scores	Group	Unadjusted	Adjusted for family income			Differences
		M (SD)	M	SE	95% CI	
Number of barriers	CP	4.27 (2.99)	3.94	0.21	[3.39, 4.49]	-0.33
	TD	0.53 (0.91)	0.82	0.20	[0.31, 1.33]	0.29
Number of supports	CP	4.56 (2.79)	4.77	0.32	[3.95, 5.59]	0.21
	TD	6.42 (3.35)	6.24	0.29	[5.48, 7.00]	-0.18
Environmental helpfulness, %	CP	73.16 (15.95)	74.24	1.28	[70.91, 77.56]	1.08
	TD	93.87 (8.79)	92.92	1.19	[89.83, 96.02]	-0.95
Environmental resources, %	CP	69.52 (14.18)	71.74	1.17	[68.71, 74.77]	2.22
	TD	89.64 (9.86)	87.69	1.09	[84.87, 90.51]	-1.95
Total environmental supportiveness, %	CP	71.57 (12.38)	73.15	1.00	[70.55, 75.74]	1.58
	TD	92.02 (7.69)	90.63	0.93	[88.22, 93.05]	-1.39

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; SE = standard error; CI = confidence interval in format [lower limit, upper limit]; Differences = differences between adjusted (controlling for family income) and unadjusted means.

Table S9. Group differences in PEM-CY community environment items scores: barriers

Environmental feature	Usually makes harder, <i>n</i> (%) [†]			
	CP	TD	<i>p</i>	ϕ
1. Physical layout	38 (34.5)	1 (0.8)	< 0.001	-0.45
2. Sensory quality	27 (24.5)	4 (3.3)	< 0.001	-0.31
3. Physical demands of activity	51 (46.4)	2 (1.6)	< 0.001	-0.53
4. Cognitive demands of activity	38 (34.5)	1 (0.8)	< 0.001	-0.45
5. Social demands of activity	19 (17.3)	2 (1.6)	< 0.001	-0.27
6. Relations with peers	13 (11.8)	1 (0.8)	0.001	-0.23
7. Attitudes	6 (5.5)	0 (0.0)	0.027	-0.17
8. Weather conditions	23 (20.9)	2 (1.6)	< 0.001	-0.31
9. Safety	29 (26.4)	15 (12.2)	0.010	-0.18

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development.

Significant *p* values are shown in bold. Effect sizes (ϕ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at *p* < 0.006).

Table S10. Group differences in PEM-CY community environment items scores: supports

Environmental feature	Usually helps, <i>n</i> (%) [†]			
	CP	TD	<i>p</i>	ϕ
1. Physical layout	24 (21.8)	31 (25.2)	0.651	0.04
2. Sensory quality	11 (10.0)	16 (13.0)	0.609	0.05
3. Physical demands of activity	15 (13.6)	26 (21.1)	0.184	0.01
4. Cognitive demands of activity	23 (20.9)	37 (30.1)	0.148	0.10
5. Social demands of activity	35 (31.8)	47 (38.2)	0.377	0.07
6. Relations with peers	45 (40.9)	57 (46.3)	0.483	0.05
7. Attitudes	56 (50.9)	54 (43.9)	0.348	-0.07
8. Weather conditions	8 (7.3)	19 (15.4)	0.082	0.13
9. Safety	13 (11.8)	29 (23.6)	0.031	0.15

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development.

Effect sizes (ϕ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at *p* < 0.006).

Table S11. Group differences in PEM-CY community environment items scores: not an issue

Environmental feature	Not an issue, n (%) [†]			
	CP	TD	p	φ
1. Physical layout	22 (20.0)	79 (64.2)	< 0.001	0.45
2. Sensory quality	31 (28.2)	84 (68.3)	< 0.001	0.40
3. Physical demands of activity	16 (14.5)	87 (70.7)	< 0.001	0.56
4. Cognitive demands of activity	20 (18.2)	72 (58.5)	< 0.001	0.41
5. Social demands of activity	16 (14.5)	65 (52.8)	< 0.001	0.40
6. Relations with peers	19 (17.3)	49 (39.8)	< 0.001	0.25
7. Attitudes	16 (14.5)	55 (44.7)	< 0.001	0.33
8. Weather conditions	29 (26.4)	71 (57.7)	< 0.001	0.32
9. Safety	40 (36.4)	51 (41.5)	0.508	0.05

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development.

Significant p values are shown in bold. Effect sizes (φ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.006$).

Table S12. Group differences in PEM-CY community environment items scores: not available/adequate resources

Resource	Usually, no, n (%) [†]			
	CP	TD	p	φ
1. Personal transportation	20 (18.2)	2 (1.6)	< 0.001	-0.28
2. Public transportation	43 (39.1)	2 (1.6)	< 0.001	-0.47
3. Programs and services	47 (42.7)	14 (11.4)	< 0.001	-0.36
4. Information	21 (19.1)	5 (4.1)	0.001	-0.24
5. Equipment and supplies	44 (40.0)	4 (3.3)	< 0.001	-0.45
6. Time	7 (6.4)	5 (4.1)	0.620	-0.05
7. Money	44 (40.0)	3 (2.4)	< 0.001	-0.47

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development.

Significant p values are shown in bold. Effect sizes (φ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.007$).

Table S13. Group differences in PEM-CY community environment items scores: available/adequate resources

Resource	Usually, yes, n (%) [†]			
	CP	TD	p	φ
1. Personal transportation	70 (63.6)	69 (56.1)	0.300	-0.08
2. Public transportation	29 (26.4)	70 (56.9)	< 0.001	0.31
3. Programs and services	25 (22.7)	11 (8.9)	0.006	-0.19
4. Information	37 (33.6)	91 (74.0)	< 0.001	0.40
5. Equipment and supplies	27 (24.5)	86 (69.9)	< 0.001	0.45
6. Time	61 (55.5)	77 (62.6)	0.330	0.07
7. Money	23 (20.9)	65 (52.8)	< 0.001	0.33

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development.

Significant p values are shown in bold. Effect sizes (φ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.007$).

Table S14. Group differences in PEM-CY community environment items scores: resources not needed

Resource	Not needed, n (%) [†]			
	CP	TD	p	φ
1. Personal transportation	1 (0.9)	33 (26.8)	< 0.001	0.37
2. Public transportation	9 (8.2)	35 (28.5)	< 0.001	0.26
3. Programs and services	10 (9.1)	90 (73.2)	< 0.001	0.65
4. Information	NA	NA	NA	NA
5. Equipment and supplies	NA	NA	NA	NA
6. Time	NA	NA	NA	NA
7. Money	NA	NA	NA	NA

Note. CP = Group of children with cerebral palsy; TD = Group of children with typical development; NA = Not applicable because “Not needed” responses are not provided for these environment items in the PEM-CY.

Significant p values are shown in bold. Effect sizes (φ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.017$).

Table S15. Cerebral palsy group differences in PEM-CY community participation items scores: percentage of children that participated in activities in relation to GMFCS level

Participation items (activity types)	Participates ever, n (%) [†]			
	GMFCS I / II / III	GMFCS IV / V	p	φ
1. Neighbourhood outings	58 (90.6)	42 (91.3)	1.000	0.01
2. Community events	50 (78.1)	36 (78.3)	1.000	0.00
3. Organized physical activities	31 (48.4)	17 (37.0)	0.316	-0.11
4. Unstructured physical activities	50 (78.1)	22 (47.8)	0.002	-0.31
5. Classes and lessons (not school-sponsored)	21 (32.8)	9 (19.6)	0.186	-0.15
6. Organizations, groups, clubs...	9 (14.1)	10 (21.7)	0.427	0.10
7. Religious or spiritual gatherings and activities	30 (46.9)	22 (47.8)	1.000	0.01
8. Getting together with other children	52 (81.3)	34 (73.9)	0.493	-0.09
9. Working for pay	2 (3.1)	0 (0.0)	0.627	-0.12
10. Overnight visits or trips	37 (57.8)	22 (47.8)	0.400	-0.10

Note. GMFCS = Gross Motor Function Classification System.

Significant p values are shown in bold. Effect sizes (φ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.005$).

Table S16. Cerebral palsy group differences in PEM-CY community participation items scores: percentage of children that participated in activities in relation to MACS level

Participation items (activity types)	Participates ever, n (%) [†]			
	MACS I / II / III	MACS IV / V	p	φ
1. Neighbourhood outings	58 (93.5)	42 (87.5)	0.447	-0.10
2. Community events	49 (79.0)	37 (77.1)	0.990	-0.02
3. Organized physical activities	33 (53.2)	15 (31.3)	0.035	-0.22
4. Unstructured physical activities	50 (80.6)	22 (45.8)	0.000	-0.36
5. Classes and lessons (not school-sponsored)	17 (27.4)	13 (27.1)	1.000	0.00
6. Organizations, groups, clubs...	8 (12.9)	11 (22.9)	0.261	0.13
7. Religious or spiritual gatherings and activities	31 (50.0)	21 (43.8)	0.647	-0.06
8. Getting together with other children	54 (87.1)	32 (66.7)	0.019	-0.25
9. Working for pay	1 (1.6)	1 (2.1)	1.000	0.02
10. Overnight visits or trips	33 (53.2)	26 (54.2)	1.000	0.01

Note. MACS = Manual Ability Classification System.

Significant p values are shown in bold. Effect sizes (φ) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.005$).

Table S17. *Cerebral palsy group differences in PEM-CY community participation items scores: percentage of children that participated in activities in relation to the level of intellectual functioning*

Participation items (activity types)	Participates ever, <i>n</i> (%) [†]				<i>p</i>	<i>V</i>
	Normal / Borderline	Mild ID	Moderate / Severe ID			
1. Neighbourhood outings	35 (97.2)	28 (90.3)	37 (86.0)	0.225	0.16	
2. Community events	32 (88.9)	26 (83.9)	28 (65.1)	0.026	0.26	
3. Organized physical activities	17 (47.2)	20 (64.5)	11 (25.6)	0.003	0.32	
4. Unstructured physical activities	30 (83.3)	19 (61.3)	23 (53.5)	0.018	0.27	
5. Classes and lessons (not school-sponsored)	10 (27.8)	12 (38.7)	8 (18.6)	0.159	0.18	
6. Organizations, groups, clubs...	7 (19.4)	6 (19.4)	6 (14.0)	0.762	0.07	
7. Religious or spiritual gatherings and activities	18 (50.0)	17 (54.8)	17 (39.5)	0.396	0.13	
8. Getting together with other children	33 (91.7)	27 (87.1)	26 (60.5)	0.001	0.35	
9. Working for pay	1 (2.8)	1 (3.2)	0 (0.0)	0.515	0.11	
10. Overnight visits or trips	25 (69.4)	16 (51.6)	18 (41.9)	0.048	0.23	

Note. ID = intellectual disability. Significant *p* values are shown in bold. Effect sizes (*V*) are rounded to two decimal points (small = 0.10–0.29; moderate = 0.30–0.49; large = 0.50–1.00).

[†] Comparison using χ^2 -test (Bonferroni adjustment of the significance level was set at $p < 0.005$).

Table S18. *Relationship between frequency of community participation and functional limitations of children with cerebral palsy*

Frequency of community participation	GMFCS	MACS	Intellectual functioning
1. Neighbourhood outings	-0.102	-0.172	0.051
2. Community events	0.030	-0.097	0.095
3. Organized physical activities	-0.080	-0.358 *	0.202
4. Unstructured physical activities	-0.106	-0.186	-0.046
5. Classes and lessons (not school-sponsored)	0.248	-0.243	-0.414 *
6. Organizations, groups, clubs...	0.298	0.045	0.175
7. Religious or spiritual gatherings and activities	-0.094	-0.013	-0.009
8. Getting together with other children	-0.029	0.007	0.064
9. Working for pay ^a	/	/	/
10. Overnight visits or trips	-0.001	-0.016	0.193

Note. GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System. Intellectual functioning is categorized as normal intellectual functioning (1), borderline intellectual functioning (2), mild intellectual disability (3), moderate intellectual disability (4), and severe intellectual disability (5). Presented are the coefficients of Spearman's rank correlation, interpreted as small (0.10–0.29), moderate (0.30–0.49) or strong (0.50–1.00).

^a No coefficients were calculated due to the small subsample size ($n = 2$).

* $p < 0.05$, two-tailed. ** $p < 0.01$, two-tailed.

Table S19. Relationship between the level of involvement in community and functional limitations of children with cerebral palsy

Level of involvement in community	GMFCS	MACS	Intellectual functioning
1. Neighbourhood outings	-0.299 **	-0.154	-0.386 **
2. Community events	-0.187	-0.111	-0.385 **
3. Organized physical activities	-0.063	-0.270	0.051
4. Unstructured physical activities	-0.269 *	-0.296 *	-0.279 *
5. Classes and lessons (not school-sponsored)	-0.155	-0.482 **	-0.463 *
6. Organizations, groups, clubs...	0.137	0.102	-0.110
7. Religious or spiritual gatherings and activities	-0.134	0.041	-0.107
8. Getting together with other children	0.133	-0.163	-0.305 **
9. Working for pay ^a	/	/	/
10. Overnight visits or trips	-0.148	-0.326 *	-0.208

Note. GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System. Intellectual functioning is categorized as normal (1) and borderline intellectual functioning (2), mild (3), moderate (4), and severe intellectual disability (5). Presented are the coefficients of Spearman's rank correlation, interpreted as small (0.10–0.29), moderate (0.30–0.49) or strong (0.50–1.00).

^a No coefficients were calculated due to the small subsample size ($n = 2$).

* $p < 0.05$, two-tailed. ** $p < 0.01$, two-tailed.

Table S20. Relationship between the PEM-CY community environment items and functional limitations of children with cerebral palsy

PEM-CY community environmental helpfulness and resources	GMFCS	MACS	Intellectual functioning
1. Physical layout	0.021	0.033	0.058
2. Sensory quality	-0.194 *	0.011	-0.122
3. Physical demands of activity	-0.068	-0.072	-0.135
4. Cognitive demands of activity	0.054	0.040	-0.326 **
5. Social demands of activity	0.046	-0.040	-0.253 **
6. Relations with peers	0.045	-0.039	-0.058
7. Attitudes	-0.004	0.016	-0.132
8. Weather conditions	-0.124	-0.004	-0.233 *
9. Safety	0.021	0.105	-0.038
10. Personal transportation	-0.019	0.016	-0.088
11. Public transportation	-0.239 *	-0.283 **	-0.104
12. Programs and services	-0.006	-0.004	-0.156
13. Information	0.126	-0.106	0.071
14. Equipment and supplies	-0.034	-0.142	-0.108
15. Time	0.001	-0.096	0.054
16. Money	-0.149	-0.133	-0.014

Note. GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System. Intellectual functioning is categorized as normal (1) and borderline intellectual functioning (2), mild (3), moderate (4), and severe intellectual disability (5). Environmental Helpfulness (items 1–9) is categorized as Usually makes harder (1), Sometimes helps, Sometimes makes harder (2), and Usually helps AND Not an issue (3). Environmental Resources (items 10–16) are categorized as Usually not available and/or adequate (1), Sometimes yes, Sometimes no (2), and Usually available and/or adequate AND not needed (3). Presented are the coefficients of Spearman's rank correlation, interpreted as small (0.10–0.29), moderate (0.30–0.49) or strong (0.50–1.00).

^a No coefficients were calculated due to the small subsample size ($n = 2$).

* $p < 0.05$, two-tailed. ** $p < 0.01$, two-tailed.

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Summary

Cerebral palsy is a well-recognized, heterogeneous condition persisting through the lifespan. In many individuals with cerebral palsy, motor disorders are associated by other comorbidities, including disturbances of sensation, perception, cognition and communication, epilepsy, emotional, behavioural and secondary musculoskeletal problems. Children with cerebral palsy face various challenges that can manifest in different ways over the life course, such as reduced and less diverse participation in daily activities at home, school and in the community, when compared to peers.

In the International Classification of Functioning, Disability, and Health (ICF), participation is defined as a person's "involvement in life situations", reflecting the interaction of the person, activity and environment. However, little is known on the participation of children with disabilities in developing countries with fewer resources, such as Serbia.

This study aimed to examine the characteristics of community participation of children with cerebral palsy in comparison to their peers with typical development and the effect of the environment on this participation, from the perspective of parents.

The results of our study confirmed that the overall participation of children with cerebral palsy in the community was lower in comparison to the participation of children with typical development. Children with cerebral palsy participated in fewer activities, less frequently and were involved to a lesser extent. Differences were also evident at the level of individual activity types.

Higher frequency, greater involvement level and a broader variety of activities were the desired types of change, as reported by parents. Parents of children with cerebral palsy highlighted engaging in activities that were beneficial for functional, motor and health status of the child, that were involving social interaction and communication and those providing children with the opportunities to develop social skills.

By comparing the structures of environmental factors, the results of our study indicated more barriers and fewer facilitators in the group of children with cerebral palsy. Additionally, the environment was overall less supportive, environmental factors were rated less often as helpful in the child's participation, and community resources were less available and/or adequate. For most children with cerebral palsy, barriers included physical and cognitive demands of typical community-based activities, as well as the physical layout of community settings. On the other hand, the supports included attitudes and actions of other members of the community towards the child,

relationships with peers and social demands of typical activities. A lack of more adequate services was confirmed.

Functional limitations children with cerebral palsy (gross motor, fine manual and intellectual functioning) were associated with the lower involvement in community-based activities. Activities affected by functional limitations were unstructured and organized physical activities, getting together with other children, and to a lesser extent, community events, neighbourhood outings, overnight visits or trips and extracurricular classes and lessons. Children with cerebral palsy with more severe levels of intellectual disability were at increased risk of fewer supporting factors and collectively less support and help from the environment.

New findings may aid the identification of families with a child with cerebral palsy who may need interventions to improve children's participation in the community environment.

Key words: participation, disability studies, International Classification of Functioning, Disability and Health, disability, children with cerebral palsy, involvement, barriers, environment, community-based activities

Sažetak

Cerebralna paraliza je prepoznatljivo, heterogeno stanje koje traje tokom čitavog životnog veka. Kod mnogih osoba s cerebralnom paralizom motorički poremećaji su praćeni različitim komorbiditetima, kao što su poremećaji čula, percepcije, kognicije i komunikacije, epilepsija, emocionalni problemi, problemi ponašanja i sekundarni mišićno-skeletni problemi. Deca s cerebralnom paralizom se suočavaju sa različitim izazovima koji se mogu manifestovati na različite načine tokom života, poput smanjenog i manje raznovrsnog uključivanja u svakodnevne aktivnosti kod kuće, u školi i u zajednici, u poređenju sa vršnjacima.

U Međunarodnoj klasifikaciji funkcionisanja, invaliditeta i zdravlja (ICF) participacija je definisana kao „uključivanje osobe u životne situacije“, što odražava interakciju osobe, aktivnosti i okruženja. Međutim, malo se zna o participaciji dece sa ometenošću u zemljama u razvoju sa manje resursa, kao što je Srbija.

Cilj ove studije je da ispitaju karakteristike participacije dece s cerebralnom paralizom u zajednici u poređenju sa njihovim vršnjacima tipičnog razvoja, kao i uticaj okruženja na ovu participaciju, iz perspektive roditelja.

Rezultati naše studije su potvrdili da je ukupna participacija dece s cerebralnom paralizom u zajednici niža u poređenju sa participacijom dece tipičnog razvoja. Deca s cerebralnom paralizom su učestvovala u manjem broju aktivnosti, manje frekventno i bila su uključena u manjoj meri. Razlike su bile evidentne i na nivou pojedinačnih tipova aktivnosti.

Veća frekventnost, viši stepen uključenosti i širi spektar aktivnosti bile su željene vrste promena, prema izveštajima roditelja. Roditelji dece s cerebralnom paralizom istakli su bavljenje aktivnostima koje su korisne za funkcionalni, motorički i zdravstveni status deteta, aktivnostima koje uključuju socijalnu interakciju i komunikaciju, kao i bavljenje onim aktivnostima koje deci pružaju prilike za razvoj socijalnih veština.

Upoređivanjem struktura sredinskih faktora, rezultati naše studije su ukazali na više barijera i manje facilitatora u grupi dece s cerebralnom paralizom. Pored toga, okruženje je u celini bilo manje podržavajuće, faktori okruženja ređe su ocenjivani kao korisni za participaciju deteta, a resursi zajednice bili su manje dostupni i/ili adekvatni. Za većinu dece s cerebralnom paralizom barijere su uključivale fizičke i kognitivne zahteve tipičnih aktivnosti u zajednici, kao i fizički raspored prostora u okruženju zajednice. S druge strane, facilitatori su se odnosili na stavove i postupke drugih članova zajednice prema detetu, odnose sa vršnjacima i socijalne zahteve tipičnih aktivnosti. Potvrđen je nedostatak adekvatnijih usluga.

Funkcionalna ograničenja dece s cerebralnom paralizom (gruba motorika, fina motorika i intelektualno funkcionisanje) povezana su sa nižim učestvovanjem u aktivnostima u zajednici. Aktivnosti na koje utiču funkcionalna ograničenja su slobodne i organizovane fizičke aktivnosti, druženje sa drugom decom, a u manjoj meri i događaji u zajednici, izlasci u komšiluku, posete ili izleti sa noćenjem i vannastavni časovi i kursevi. Deca s cerebralnom paralizom sa težim nivoima intelektualne ometenosti su bila u povećanom riziku od manjeg broja faktora podrške i zbirno manje podrške i pomoći okoline.

Nova saznanja bi mogla biti od pomoći u identifikovanju porodica sa detetom s cerebralnom paralizom kojima bi mogle biti potrebne intervencije da bi se poboljšala participacija dece u okruženju zajednice.

Ključne reči: participacija, studije ometenosti, Međunarodna klasifikacija funkcionisanja, invalidnosti i zdravlja, ometenost, deca s cerebralnom paralizom, uključenost, barijere, sredinsko okruženje, aktivnosti u zajednici

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Main research interests include, but are not limited to, the specificities of marginalized groups, especially when it comes to participation of persons with disabilities, individual and family quality of life and family-centred approach in rehabilitation services and professional support. Clinical interests refer to the phenomenology and epidemiology of motor disorders and developmental disabilities and rehabilitation, especially in the clinical picture of cerebral palsy.

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