

This is the peer-reviewed version of the article:

Golubović, Š.; Božić, D.; Ilić, S. Support Needs of Children with Cerebral Palsy. International Journal of Disability Development and Education 2021.

<https://doi.org/10.1080/1034912X.2020.1731436>.



This work is licensed under:

[Attribution-NonCommercial-NoDerivatives 4.0 International \(CC BY-NC-ND 4.0\)](https://creativecommons.org/licenses/by-nc-nd/4.0/)

# Support Needs of Children with Cerebral Palsy

## ABSTRACT

**Objectives:** Support needs refer to the type, intensity and time necessary for a person to participate in the activities of daily living. The aim of this paper is to show the profile of support needs for children with cerebral palsy with regards to the level of functional ability of the upper and lower extremities.

**Methods:** The sample comprised 40 respondents diagnosed with spastic cerebral palsy (23 girls (57.5%) and 17 boys (42.5%). The age range was from 7 to 14 years (Mean age = 10.33; SD = 3.31). The instruments used in the present study include the Supports Intensity Scale – Children’s Version (SIS-C), The Gross Motor Function Classification System and Manual Ability Classification System for Children with Cerebral Palsy.

**Results:** The reliability of the SIS– C was  $\alpha = 0.97$ . The highest level of support needs was within the four domains. Support Needs Indexing showed significant differences in relation to the development of manual ability levels ( $F = 2.56$ ;  $p = 0.05$ ) and gross motor function levels ( $F = 3.25$ ;  $p = 0.03$ ).

**Conclusions:** The results obtained indicate that children with cerebral palsy need support in individual life domains, in which, a model for planning interventions could be provided.

## KEYWORDS

Cerebral Palsy; gross motor function; manual abilities; supports intensity scale

## Introduction

Cerebral palsy (CP) is a non-progressive chronic disorder caused by nonprogressive disturbances in the developing foetal and infant brain. It is manifested by the disruption of posture and movement, the problems of performing fine and gross motor skills with associated co-morbidities such as: sensory impairments, intellectual disability, speech delay and behavioural disorders (Bax et al., 2005; Katušić, 2012; Rosenbaum et al., 2007). Nearly half of the children with cerebral palsy have problems associated with intellectual disability characterised by lower than average intellectual functioning, existing concurrently with related limitations in adaptive skills (Cans et al., 2002; Türkoğlu, Türkoğlu, Çelik, & Uçan, 2017).

Cerebral palsy is often accompanied by multiple disabilities which additionally hinder the performance of various daily life activities, social participation and negatively affect all life domains (Bax et al., 2005; Horsman, Suto, Dudgeon, & Harris, 2010; Imms, Reilly, Carlin, & Dodd, 2008). This diversity, as well as the level of disability, affect the dependence of

children with CP on other people as well as the type and intensity of support needs they require. With respect to The International Classification of Functioning, Disability and Health (ICF) (International classification of functioning, disability, and health: ICF, 2001), we can conclude that disability associated with CP does not only reflect a child's health condition but also the factors of the environment in which they live; thus representing a social construct rather than a purely biological or psychological one. The environment in which a child lives has an effect on their behaviour as well as their ability to complete activities and tasks. Capacities are a child's ability to carry out a task or activity in a given environment. Limitations in a child's capacities assume a need for extra support in personal and home care, as well as educational and social support (Meester-Delver, Beelen, Hennekam, Hadders-Algra, & Nollet, 2006).

The term support refers to resources and strategies that aim to promote the development, education, interests and personal well-being of a person in order to improve their individual functioning (Thompson et al., 2009). Support provided to a child allows them to achieve their personal goals as well as a better quality of life (Thompson, Tasse, & McLaughlin, 2008). The results of Dobhal and associates research show that 30% of children diagnosed with cerebral palsy have poor quality of life (Dobhal, Juneja, Jain, Sairam, & Thiagarajan, 2014). In relation to typically developing children, children with cerebral palsy have a lower quality of life in the domains of emotional and physical well-being (Liptak et al., 2001). Less need for support has been observed in children with fewer comorbidities, children with higher functional mobility, families that have greater socio-economic resources, and those with access to high-quality services, which accordingly represent protective factors for the need for extra support (Almasri, O'Neil, & Palisano, 2014; Almasri et al., 2012, 2011). A modern approach implies movement from focusing on deficit to focusing on support needs.

The level of motor function impairment in children with CP has a significant effect on the psychomotor development of children, the process of integration in their social environment, functioning in all life domains and consequently on their growing up (Milićević, Potic, Nedovic, & Medenica, 2012). Levels of motor impairment, ability to move around, communication skills and manual abilities are directly related to the social participation levels (Beckung & Hagberg, 2002; Ehrmann, Aeschleman, & Svanum, 1995; Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006). Lack of experience, skills and knowledge due to an underlying condition of the disease, as well as passiveness and dependency, may lead to significantly reduced children's involvement in formal and informal everyday activities, both in their homes and communities where they live (Blum, Resnick, Nelson, & St Germaine, 1991; Imms et al., 2008; Shikako-Thomas, Majnemer, Law, & Lach, 2008; Slavkovic, Golubovic, Kalaba, & Brocilo, 2017). Imms and associates (Imms et al., 2008) have come to the conclusion that children with CP, compared to typically developing children of similar ages, participate in all aspects of social life and social functioning with significantly less intensity. As compared to typically developing children, children with motor impairments participate less frequently in physical activities such as games in various environments, sports, social activities such as community visits, going out on the town, or mastering various skills such as playing an instrument or bicycle riding (King, Law, Hurley, Petrenchik, & Schweltnus, 2010).

Given that greater individual's limitations require higher levels of support it is important to identify the types of support needs that will help reduce the differences between

personal deficiencies and the environmental requirements, improve the functioning as well as achieve desired personal outcomes (Schalock, Verdugo, Gomez, & Reinders, 2016). Full social inclusion of individuals can only be expected if adequate support is provided to them both through formal support, provided by professionals and informal, through persons who are around them every day (Petrovic, Stojisavljević, & Tadić, 2012; Smit, Sabbe, & Prinzie, 2011).

It is highly important that children with CP are capable of functioning in accordance with their functional abilities within all domains (Parkes, McCullough, & Madden, 2010), and it is therefore necessary to determine the level of supports needed in order to plan adequate resources, various types and intensities of supports so the child can be fully engaged (Schalock et al., 2016; Thompson et al., 2009; Wehmeyer et al., 2009). Pattern and intensity of support needs will vary, depending on the personal and environmental factors. The level of the individual's functioning and impairment followed by environmental conditions will influence needs areas.

Using the Supports Intensity Scale for Children (Thompson et al., 2016) has helped us to recognise needs areas in different domains of child functioning. Support needs are recognised in a medical domain such as respiratory and skin care or feeding assistance; health and safety activities which include physical fitness and taking care of emotional wellbeing. In home life activities these needs are shown in eating, dressing, toileting. Activities connected with community participation are moving around or in school participation and participation in activities in common school areas. Self-determination is recognised as the ability to make decisions, set personal goals, express personal feelings.

Although it has been recognised that children should receive support for their proper development, daily functioning, and equal participation in community, the number of studies that have addressed this issue is, in Serbia, still small. The aim of this paper is therefore to investigate the correlation between the support needs and functional ability of upper and lower extremity for children with CP.

## **Method**

### **Participants**

The sample consisted of 40 examinees with a diagnosis of spastic hemiparesis (26), and spastic quadriplegia (14). Of the total number of examinees, 34 were with intellectual disability, of whom 20 with mild and 14 with moderate. Diagnoses were made by medical doctors at medical centres and data about the diagnoses and level of intellectual functioning were obtained from the available medical and school records. Exclusion criteria were: presence of severe sensory deficit (sight and hearing), presence of other neurological and psychiatric conditions, as well as the age limit of 15 years. Girls comprised a slightly higher percentage (57.5%) compared with (42.5%) boys. The ages of children involved ranged from 7 to 14 years (Mean age = 10.33, SD = 3.31). The research with these children was conducted at their schools, and the scale for assessing support needs was filled in by their parents with help of a qualified interviewer. Parents were given oral and written instructions for completing the scale which they returned to the examiner when they filled it in. A qualified interviewer evaluated every completed scale. The research was approved by the Ethics Committee of the Faculty of Medicine and the written informed

consent was signed by parent/guardian before they were presented with the scale. The research was carried out in three cities on the territory of Serbia. Participation in the research was voluntary, and anonymity was guaranteed.

## Instruments

For research purposes, three instruments were used. Supports intensity scale – Children’s version (SIS-C) is an instrument for measuring the intensity of support needs of children with intellectual and developmental disabilities, between ages 5 to 16 (Thompson et al., 2016). According to the authors of the scale, SIS-C can also be used as a tool for developing individual support plans, and as an assessment tool for resource allocation. The SIS-C evaluates the support needs, not deficits (Thompson et al., 2014). The scale has two sections: Part I assesses Exceptional Medical and Behavioural Needs, which may require a significant level of support, regardless of the intensity of support needs in other spheres of life, and Part II assesses seven areas: Home Living (e.g. Keeping self-occupied during unstructured time); Community & Neighbourhood (e.g. Participating in leisure activities that require physical activity and that do not require physical exertion); School Participation (e.g. Participating in activities in common school areas); School Learning (e.g. Learning academic skills, Learning and using metacognitive strategies); Health & Safety (e.g. Maintaining physical fitness – emotional well-being -health and wellness); Social Activities (e.g. Respecting the rights of others, maintaining conversation); and Advocacy (e.g. Setting personal goals, taking action and attaining goals). For the purposes of this research, only the second part of the scale was applied. All the domains include eight or nine items that assess the 3 dimensions of support needs: type (the nature of support needed, 0 = no support needed 1 = monitoring, 2 = verbal/gestural prompting, 3 = partial physical assistance, 4 = full physical assistance); frequency (how often support is needed: 0 – negligible, 1 – infrequently, 2 – frequently; 3 – very frequently, 4 – always); and daily support time (how much time by another person is needed to provide support.; 0-none, 1-less than 30 min, 2 h 30 minutes to less than 2 h, 3 to 2 h less than 4 h, 4 h or more (Thompson et al., 2016). Strong reliability of a Cronbach’s alpha above 0.90 for the whole scale and for each domain was confirmed by the authors of the scale and other researchers (Guillen Martin, Adam Alcocer, Verdugo Alonso, & Gine Gine, 2017; Verdugo, Guillen, Arias, Vicente, & Badia, 2016). Respondents were parents who provided answers with help and explanations of professionals.

Manual Ability Classification System for Children with Cerebral palsy (MACS) (Eliasson et al., 2006) is a five-level system, where Level I include children with minor limitations, while children with severe functional limitations will usually be found at Levels IV and V. MACS evaluate show children handle age-appropriate objects at home, school and in community settings. It is intended for children aged 4 to 18 years. It does not explain the reasons for impaired manual abilities nor the function and quality of each hand separately. It spans the entire spectrum of functional limitations found among children with cerebral palsy. It describes five levels based on the children’s ability to handle objects and their need for assistance or adaptation in order to perform tasks. It is a five-level system, where Level I includes children with minor limitations, while children with severe functional limitations will usually be found at Level V. MACS has good validity and reliability.

The confidence interval according to the authors of the scale is 0.96–0.98. The observers were professionals.

The Gross Motor Function Classification System (GMFC) for cerebral palsy provides a method of describing the functional ability in children with CP (Mutlu, Kara, Gunel, Karahan, & Livanelioglu, 2011). It is based on self-initiated movements with an emphasis on sitting, transfers, and mobility (Gross Motor Functional Classification System Internet, n.d.).

This classification system differentiates five levels. The focus is to determine which level best reflects the child's or youth's present abilities and limitations in gross motor function. Level I indicates that there are no restrictions on movement, while Level V denotes that a person needs extensive assistance of adaptive equipment; GMFCS has good validity and reliability. The confidence interval confirmed by the authors of the scale is 0.95–0.97. The observers were professionals.

## Statistical Analysis

The SPSS 20.0 software package was used to enter and process data. For the purposes of analysing and describing the structure of the sample by relevant variables, frequency and percentage procedures were used to represent a particular category or response. Statistical methods involved in carrying out a study include descriptive statistics to determine the measure of central tendency (arithmetic mean), measure of variability (standard deviation) and extreme values (minimum and maximum values) of numerical features that had been observed. Comparative statistics were performed using the one-factor analysis of variance (ANOVA) and the Pearson linear correlation coefficient. In the analyses applied, statistically significant differences were at the significance level of 95% ( $p < 0.05$ ). For checking the reliability of the scale as a whole and the selected subscale/ domains, the Cronbach alpha coefficient was used as a measure of internal consistency.

## Results

### Preliminary Statistical Analyses

Internal Consistency for the total SIS-C scale, as well as the individual domains of this scale, were checked by calculating the Cronbach alpha coefficient.

Based on data derived from the present research, the reliability of the Supports Intensity Scale, on the whole, was  $\alpha = 0.97$ , which is excellent reliability while the reliability for individual subscales ranged from  $\alpha = 0.45$  to 0.96. More precisely, all the scales with the exception of Exceptional Behavioural Needs and Exceptional Medical and Behavioural Support Needs had excellent reliability. The highest individual reliability was  $\alpha = 0.96$  for a Health & Safety scale. Cronbach's alpha of the remaining scales were: Home Living  $\alpha = 0.93$ ; Community & Neighbourhood  $\alpha = 0.92$ ; School Participation  $\alpha = 0.94$ ; School Learning  $\alpha = 0.92$ ; Social Activities  $\alpha = 0.93$ ; Advocacy  $\alpha = 0.94$ .

Further, for the purpose of this study, we will analyse the results from the second part of SIS-C, which comprise seven sections and include activities for Home Living; Community & Neighbourhood; School Participation; School Learning; Health & Safety; Social Activities; and Advocacy.

**Table 1.** The mean of standard values and basic characteristics of distribution of SIS domains.

	AS	SD	Sk	Ku
Home Living	10,20	2,79	0,26	0,13
Community & Neighbourhood	9,18	2,60	0,53	0,05
School Participation	8,43	2,52	0,43	2,38
School Learning	6,08	3,09	0,27	0,33
Health & Safety	7,18	2,72	0,28	0,07
Social Activities	6,45	2,22	0,00	2,48
Advocacy	6,90	3,05	0,82	2,29

AS: Mean; SD: standard deviation; Sk (Skewness) indicator of the asymmetry of a distribution; Ku (Kurtosis) indicator of flatten distribution

As shown in [Table 1](#) the analysis performed indicates that within most of the examined domains distribution of responses corresponds to a normal distribution. With the exception of several domains, where there is a slight deviation from distribution in relation to the normal distribution, which can be observed using the values of Skewness and Kurtosis (values above +1.5). A deviation was recorded in the domains of School Participation, Social Activities, and Advocacy. By assessing the obtained average standard domain values, it can be viewed that there is the greatest need for support in the Home Living, Community & Neighbourhood, School Participation domains. The lowest level of support in the group of children with cerebral palsy is in the School Learning and Social Activities domains.

#### Relationship between Support Needs and Motor Ability

[Table 2](#) shows the distribution of respondents in relation to the gross motor function levels and manual abilities.

As compared to manual abilities, the obtained results show that out of five given levels based on the child's ability to handle objects and the need for help or adaptation to perform tasks, the greatest number of children (45%) grouped at level three – handle objects with difficulties; need assistance in the preparation and/or adaptation to activities.

As for the Gross Motor Function, the obtained results indicate that with respect to the frequency of some response categories, of the five given levels, based on voluntarily initiated movement with emphasis on sitting, transfer and mobility, the most frequent corresponds to level five – transported in a manual wheelchair by others (about 45%).

Pearson's linear correlation coefficient ([Table 3](#)) was used to determine whether there is an association between support need domains (measured on the SIS-C) and motor function and manual ability.

Regarding the relationship between the SIS-C domain scores and the gross motor function and manual ability classifications, there is a statistically significant relationship

**Table 2.** Distribution of respondents in relation to the GMFC and MACS levels.

Level	GMFC	MACS
I	-	6 (15%)
II	8 (20%)	7 (17,5%)
III	7 (17,5%)	18 (45%)
IV	7 (17,5%)	5 (12,5%)
V	18 (45%)	4 (10%)

**Table 3.** Correlation between the SIS domain standardised scores and two systems of classification.

	GMFCS	MACS
Home Living	0,14	0,05
Community & Neighbourhood	0,30	0,17
School Participation	0,39*	0,41**
School Learning	0,30	0,35*
Health & Safety	0,51**	0,40**
Social Activities	0,11	0,44**
Advocacy	0,30	0,45**

\*\*\* $p < .001$ , \*\* $p < .01$ , \* $p < .05$ ; MACS: *The Manual Ability Classification System*; GMFCS: *Gross Motor Function Classification system*.

and their intensity values range from moderate to high (0.35 to 0.51), in which they all demonstrate a linear relationship. A relationship between the manual ability domain has been demonstrated using MACS levels and SIS-C scores, and found to have the highest correlation within the Advocacy scale domain ( $r = 0.45$ ;  $p < 0.01$ ). Moreover, using the manual ability classification system a moderate, positive correlation was measured within the Social Activities ( $r = 0.44$ ;  $p < 0.01$ ), Health & Safety ( $r = 0.40$ ;  $p < 0.01$ ), School Learning ( $r = 0.35$ ;  $p < 0, 05$ ) and School Participation domains ( $r = 0.41$ ;  $p < 0.01$ ). As for the gross motor function classification (GMFC), the highest correlation has been recorded within the Health & Safety domain as measured on the SIS-C ( $r = 0.51$ ;  $p < 0.01$ ). A moderate positive linear correlation was found between the remaining SIS-C domains and GMFC, as well as with the School Participation domain ( $r = 0.39$ ;  $p < 0.05$ ). This type of relationship between the examined phenomena (positive correlation) indicates that a higher functional ability in relation to gross motor function and manual abilities is accompanied by a lower intensity of support needs domains of the SIS-C and vice versa.

### Differences between Upper Vs. Lower Functional Ability of CP

A Support Needs Index of functional abilities of children with cerebral palsy based on the association between gross motor function and manual ability is shown in [Figure 1](#).

One-factor analysis of variance within the group of children included in the study, revealed statistically significant differences shown by the Support Needs Index with regard to the manual ability level ( $F = 2.56$ ;  $p = 0.05$ ). When the difference is observed between the individual levels according to which the respondents were grouped, MACS results demonstrate that the child is less functional and thus classified as MACS level IV or V, resulting in above the average SIS support needs index which in turn indicates a worse functionality.

Furthermore, findings from ANOVA demonstrated statistically significant differences by the Support Needs Index and with respect to the gross motor function level ( $F = 3.25$ ;  $p = 0.03$ ). As for the difference related to GMFC levels according to which the respondents were classified, lower level of child's independence classified at GMFC levels IV and V showed that the Support Needs Index on the SIS scale was above average, indicating lower functionality.

## Discussion

Recognising the support needs of children with disabilities and developmental delays is important so that optimal conditions for their development within their communities can



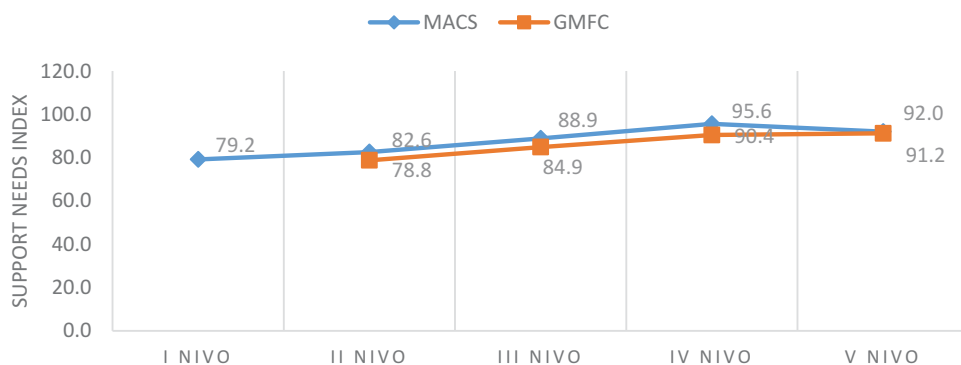


Figure 1. Support needs index in relation to the level of GMFC and MACS.

be provided. The results have shown that the greatest intensity of support needs was exhibited in the following domains: Home Living, Community & Neighbourhood, School Participation. Limitations in motor development and intellectual functioning in children with CP lead to their lower participation in these activities. Bearing in mind that almost half of the respondents in our sample do not move independently, the obtained information is not surprising given that the need has been pronounced most in the domains that are related to the mobility across home, school, and out-of-school settings. Restrictions on movement reduce opportunities for engagement in joint peer activities and special events. Reduced opportunities for sharing experiences were accompanied by difficulties in adopting and obeying rules in school and society. Children find it more difficult to adapt to the environmental requirements, which means that additional support is needed to overcome these barriers. Because of the problems in gross motor functions, as well as in manual abilities, children with CP involved in the present study needed other person's assistance with household chores, taking food, maintaining personal hygiene, and other activities of daily living, sports, and recreation. Research results by Chan, Lau, Fong, Poon, and Lam (2005) showed that 86% of children with cerebral palsy participate in leisure activities (going to a restaurant, shopping or playgrounds) while 54% of children participate in recreational activities, which is a significantly smaller percentage in relation to peers from a typical population (Chan et al., 2005). Also, these data point to the fact that children with CP participate significantly less often in activities at home when compared with their typically developing peers (Longo, Badia, & Orgaz, 2013). In children with cerebral palsy, the primary limitations in motor development and various associated comorbidities make their involvement in the social environment, emotional, cognitive and intellectual functioning difficult, thus leading to a greater degree of intense and continuous support needs (Milićević et al., 2012).

The lowest intensity of support needs, in the group of children with cerebral palsy who participated in the present study, was in the School Learning and Social Activities domains. This data underlines the fact that all respondents attend schools for children with disabilities and that they are educated according to Individualised Education Plan. Therefore, educational requirements are adapted to their learning abilities and in this way support has already been provided in this domain. Also, social activities take place in the least restrictive environment possible for children with CP and support is thus provided

either through the contents, resources, and materials or places where the activities are carried out. Previous studies have confirmed that domains such as physical independence, mobility, and social integration were more disturbed than it was the case with school, social and economic problems (Dobhal et al., 2014).

With regard to the relationship of the SIS-C domain scores and gross motor function classification systems and manual abilities in the group of children with cerebral palsy, there is a certain number of statistically significant correlations. GMFC correlates positively with two of the seven SIS-C domains (Health & Safety and School Participation) while a positive correlation with MACS is found in five of the seven support domains (Advocacy, Social Activities, Health & Safety, School Learning, School Participation). This suggests that the support needs are more related to assistance with movements rather than to the ability to use hands to manipulate and handle objects. A higher level of manual ability functions was accompanied by lower intensity support, that is, a lower degree of motor impairments, manual ability, and communication skills leads to a higher frequency of participation in the activities (Park & Kim, 2015).

The absence of correlation is found in the domains of Home Living and Community & Neighbourhood. The possible reason for this is that parents provide the largest share of household activities. It is possible that parents consider their children's health condition the reason why they should not perform any activity in their homes, that is, they do not expect that she/he could perform it by himself/herself with adequate assisted support. On the other hand, community activities are more often related to socialising and moving than to manipulation activities.

Children with developmental delays participate in home-related activities with a lower frequency while better gross motor skills, as well as a lower degree of intellectual disability, are associated with higher frequency of participation in home, out-of-school activities and community activities (Michelsen et al., 2009). Also, Park and Kim research study (2015) showed that at the age of 12 years, a greater degree of deficiency in motor skills, manual and communication abilities leads to a less frequent engagement in different activities (attendance of cultural events, household chores, going shopping, community participation).

Difficulties in motor skill functioning of children with CP have an impact on support needs and they can significantly influence successful performance of everyday activities, as well as the level of participation achieved (Axelsson & Wilder, 2013). The obtained results, which could be surprising, show that participants with the lowest level of manual functional skills display fewer needs for support than participants who are at the fourth level on MACS. A possible explanation could be found in the structure of the participants. The sample consisted of participants who were different not only in terms of manual ability but in intellectual capacity. If the participants from level five were with a mild intellectual disability or were older than participants from level four that could explain a lower level of support needs. These results must be further evaluated and verified through comprehensive research, with a large number of participants and with controlled factors that could have an influence on support needs.

Support Needs Assessment should become an integral part of the evaluation process since the results obtained could indicate specific support needs of children with developmental disabilities. As such, each child's needs for support expressed through individual profiles become the starting point for Individual Support Plan Development, and by identifying the exact domains for supporting the needs, a model for planning

interventions could be provided, facilitating cooperation between the professionals, family and a child with developmental disabilities that will contribute to their equal involvement and participation in school, community and at home.

Bearing in mind that in our country there is not much research into this topic, the study's limitations could be overcome through further and more numerous research studies, which will include a greater number of respondents, different age groups, and children with other developmental disabilities. In addition, employing more research instruments for objectifying the functional ability of respondents could contribute to a better understanding of the needs of children with CP.

## Conclusions

The results of the study show that there is a need for support in children affected by cerebral palsy in the domains of School Participation, Community & Neighbourhood, and Home Living. They are in correlation with the level of functional ability of a child, that is, the children who have a higher level of functional independence and less impairment of gross motor skills and manual ability, show to a lesser extent the needs for support.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## References

- Almasri, N., Palisano, R. J., Dunst, C., Chiarello, L. A., O'Neil, M. E., & Polansky, M. (2012). Profiles of family needs of children and youth with cerebral palsy. *Child: Care, Health and Development*, 38(6), 798–806.
- Almasri, N. A., O'Neil, M., & Palisano, R. J. (2014). Predictors of needs for families of children with cerebral palsy. *Disability and Rehabilitation*, 36(3), 210–219.
- Almasri, N. A., Palisano, R. J., Dunst, C. J., Chiarello, L. A., O'Neil, M. E., & Polansky, M. (2011). Determinants of needs of families of children and youth with cerebral palsy. *Children's Health Care*, 40(2), 130–154.
- Axelsson, A. K., & Wilder, J. (2013). Frequency of occurrence and child presence in family activities: A quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development. *International Journal of Developmental Disabilities*, 60(1), 13–25.
- Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., Paneth, N., Dan, B., ... Damiano, D. (2005). Proposed definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology*, 47(8), 571–576. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16108461>
- Beckung, E., & Hagberg, G. (2002). Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Developmental Medicine and Child Neurology*, 44(5), 309–316. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12033716>
- Blum, R. W., Resnick, M. D., Nelson, R., & St Germaine, A. (1991). Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*, 88(2), 280–285. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/1861926>

- Cans, C., Guillem, P., Arnaud, C., Baille, F., Chalmers, J., McManus, V., ... SCPE. (2002). Prevalence and characteristics of children with cerebral palsy in Europe. *Developmental Medicine and Child Neurology*, 44(9), 633–640.
- Chan, H. S., Lau, P. H., Fong, K. H., Poon, D., & Lam, C. C. (2005). Neuroimpairment, activity limitation, and participation restriction among children with cerebral palsy in Hong Kong. *Hong Kong Medical Journal*, 11(5), 342–350. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16219953>
- Dobhal, M., Juneja, M., Jain, R., Sairam, S., & Thiagarajan, D. (2014). Health-related quality of life in children with cerebral palsy and their families. *Indian Pediatrics*, 51(5), 385–387. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/24953580>
- Ehrmann, L. C., Aeschleman, S. R., & Svanum, S. (1995). Parental reports of community activity patterns: A comparison between young children with disabilities and their nondisabled peers. *Research in Developmental Disabilities*, 16(4), 331–343. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/7480959>
- Eliasson, A. C., Kruminde-Sundholm, L., Rosblad, B., Beckung, E., Arner, M., Ohrvall, A. M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. *Developmental Medicine and Child Neurology*, 48(7), 549–554. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16780622>
- Guillen Martin, V. M., Adam Alcocer, A. L., Verdugo Alonso, M. A., & Gine Gine, C. (2017). Comparison between the spanish and catalan versions of the Supports Intensity Scale for Children (SIS-C). *Psicothema*, 29(1), 126–132. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/28126070>
- Horsman, M., Suto, M., Dudgeon, B., & Harris, S. R. (2010). Ageing with cerebral palsy: Psychosocial issues. *Age and Ageing*, 39(3), 294–299. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/20178997>
- Imms, C., Reilly, S., Carlin, J., & Dodd, K. (2008). Diversity of participation in children with cerebral palsy. *Developmental Medicine and Child Neurology*, 50(5), 363–369. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/18355337>
- International classification of functioning, disability, and health: ICF. (2001). Version 1.0. Geneva: World Health Organization, [2001] ©2001.
- Katušić, A. (2012). Cerebralna paraliza: Redefiniranje i reklasifikacija. *Hrvatska Revija Za Rehabilitacijska Istraživanja*, 48(1), 117–126. Retrieved from <https://hrcak.srce.hr/79027>
- King, G., Law, M., Hurley, P., Petrenchik, T., & Schwellnus, H. (2010). A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *International Journal of Disability, Development and Education*, 57(1), 77–107.
- Lawlor, K., Mihaylov, S., Welsh, B., Jarvis, S., & Colver, A. (2006). A qualitative study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in northeast England. *Pediatric Rehabilitation*, 9(3), 219–228. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17050400>
- Liptak, G. S., O'Donnell, M., Conaway, M., Chumlea, W. C., Wolrey, G., Henderson, R. C., ... Stevenson, R. D. (2001). Health status of children with moderate to severe cerebral palsy. *Developmental Medicine and Child Neurology*, 43(6), 364–370. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11409824>
- Longo, E., Badia, M., & Orgaz, B. M. (2013). Patterns and predictors of participation in leisure activities outside of school in children and adolescents with Cerebral Palsy. *Research in Developmental Disabilities*, 34(1), 266–275. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/22989575>
- Meester-Delver, A., Beelen, A., Hennekam, R., Hadders-Algra, M., & Nollet, F. (2006). Predicting additional care in young children with neurodevelopmental disability: A systematic literature review. *Developmental Medicine and Child Neurology*, 48(2), 143–150.
- Michelsen, S. I., Flachs, E. M., Uldall, P., Eriksen, E. L., McManus, V., Parkes, J., ... Colver, A. (2009). Frequency of participation of 8–12-year-old children with cerebral palsy: A multi-centre cross-sectional European study. *European Journal of Paediatric Neurology: Official Journal of the European Paediatric Neurology Society*, 13(2), 165–177. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/18571944>

- Miličević, M., Potic, S., Nedovic, G., & Medenica, V. (2012). Predictors of Social Participation of Children with Cerebral Palsy in School Environment/Prediktori socijalne participacije djece sa cerebralnom paralizom u kolskom okru enju.
- Mutlu, A., Kara, O. K., Gunel, M. K., Karahan, S., & Livanelioglu, A. (2011). Agreement between parents and clinicians for the motor functional classification systems of children with cerebral palsy. *Disability and Rehabilitation*, 33(11), 927–932. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/20815692>
- Park, E. Y., & Kim, W. H. (2015). Relationship between activity limitations and participation restriction in school-aged children with cerebral palsy. *The Journal of Physical Therapy Science*, 27(8), 2611–2614. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/26357445>
- Parkes, J., McCullough, N., & Madden, A. (2010). To What Extent Do Children with Cerebral Palsy Participate in Everyday Life Situations? *Health Soc Care Community*, 18(3), 304-315. doi:10.1111/j.1365-2524.2009.00908.x
- Petrovic, B., Stojisavljević, D., & Tadić, K. (2012). Pojam o sebi osoba sa intelektualnim te ko ama – Implikacije za razvoj programa podr ke.
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., ... Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology*, 109, 8–14. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17370477>
- Schalock, R. L., Verdugo, M. A., Gomez, L. E., & Reinders, H. S. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities*, 121(1), 1–12. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/26701070>
- Shikako-Thomas, K., Majnemer, A., Law, M., & Lach, L. (2008). Determinants of participation in leisure activities in children and youth with cerebral palsy: Systematic review. *Physical & Occupational Therapy in Pediatrics*, 28(2), 155–169. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/18846895>
- Slavkovic, S., Golubovic, S., Kalaba, S., & Brocilo, I. (2017). Engagement of children with cerebral palsy in daily life. *PONS - Medicinski Casopis*, 14(2), 41–45.
- Smit, W., Sabbe, B., & Prinzie, P. (2011). Reliability and validity of the Supports Intensity Scale (SIS) measured in adults with physical disabilities. *Journal of Developmental and Physical Disabilities*, 23 (4), 277–287. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/21841900>
- Thompson, J., Wehmeyer, M., Hughes, C., Shogren, K., Palmer, S., & Seo, H. (2014). The Supports Intensity Scale–Children’s Version: Preliminary Reliability and Validity.
- Thompson, J. R., Bradley, V. J., Buntinx, W. H., Schalock, R. L., Shogren, K. A., Snell, M. E., ... Yeager, M. H. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, 47(2), 135–146. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19368481>
- Thompson, J. R., Tasse, M., & McLaughlin, C. (2008). Interrater reliability of the Supports Intensity Scale (SIS). *American Journal of Mental Retardation*, 113(3), 231–237.
- Thompson, J. R., Wehmeyer, M. L., Hughes, C., Shogren, K. A., Little, T. D., Copeland, S. R., & Tassé, M. J. (2016). *Supports intensity scale-children’s version: User’s manual*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Türkoğlu, G., Türkoğlu, S., Çelik, C., & Uçan, H. (2017). Intelligence, functioning, and related factors in children with cerebral palsy. *Noro Psikiyatri Arsivi*, 54(1), 33–37.
- Verdugo, M. A., Guillen, V. M., Arias, B., Vicente, E., & Badia, M. (2016). Confirmatory factor analysis of the supports intensity scale for children. *Research in Developmental Disabilities*, 49–50, 140–152. . Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/26707926>
- Wehmeyer, M., Chapman, T. E., Little, T. D., Thompson, J. R., Schalock, R., & Tasse, M. J. (2009). Efficacy of the Supports Intensity Scale (SIS) to predict extraordinary support needs. *American Journal on Intellectual and Developmental Disabilities*, 114(1), 3–14. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19143461>