

Predictors of Social Participation of Children with Cerebral Palsy in School Environment

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Abstract

The aim of this paper is to allocate studies dealing with the identification of predictors and the definition of the importance, nature and extent of social participation of children with cerebral palsy in the school environment. A review of literature dealing with the subject will be carried out and the knowledge of the field systematized. The selected studies will be analyzed and the predictors and determinants of participation defined. Based on the analysis guidelines for the upgrade of social participation of children with cerebral palsy will be outlined and suggestions for the implementation of this knowledge in the practical work in inclusive terms given.

The results suggest that there is a complex relation between disability, participation and school environment and that the predictors cannot be viewed as isolated entities but only as combined models of the interactive physical and cognitive-behavioral variables. The key steps in the professional intervention comprise the development of strategies that will enable children with cerebral palsy to take full advantage of the opportunities provided by daily school activities in terms of active social inclusion.

Key words: social integration, disability, peers.

Introduction

Full social participation of children with cerebral palsy (hereinafter: CP) refers to their inclusion in all activities within the family, peer, school and leisure environment in the same volume and extent as is the participation of other children without disabilities. Milićević et al. (2011) report the findings of numerous studies stating that participation

in daily activities is crucial for the quality of life of children with CP and that it represents an irreplaceable predictor of their adequate development. Regardless of what we know about the significance of social participation at the very early age and throughout childhood, there is an important risk of the exception of children with CP from the normal activities within the family and/or community (King et al., 2003). This inevitably leads to social exclusion. According to Trgovčević and Kljajić (2011) the society influences the development of an individual throughout childhood and has a major influence on the entire human life. They also consider all factors to be equally important for the social inclusion process: the person himself, family, school and peers, regional and local social community as well as the entire social policy of the society in which the person lives. This problem is additionally emphasized by the fact that growing up leads to more demanding social and environmental requirements which impose the need for change in the ways and the extent of the participation of each individual in all segments of life and all social activities as a basic precondition for social integration (Milićević et al., 2011).

Professional and scientific communities do not agree on the determinants they find to be crucial for the (non)realization of social participation in general, or in a specific area of social functioning of children with CP. That is why Ilić and Nikolić (2001) believe that the process of social integration of persons with the consequences of CP is hindered or disabled by the difficulties in the motor functioning. Moreover, Rapačić and Nedović (2011) state that the great variability of motor dysfunction in terms of type and intensity as well as the frequent combination with the intellectual, sensory-perceptual and speech difficulties make this population of children and young people very unreliable for planning uniformed system solutions, either within the educational, rehabilitation or social programmes.

Based on an extensive literature review, Milićević and Potić (2011) have concluded that the understanding of the complexity and diversity of the participation of children with CP of different ages and in different environments demands a wider focus than is a simple determination of their individual performances in certain activities and aspects of personal and social lives. Moreover, they have found that the level of the achieved social participation of children with CP is directly dependent on individual determinants, namely those related to the child itself, and the environmental socio-cultural factors as well as their interaction. The authors have found that out of the individual factors which determine social participation of children with CP, the most frequent ones given in the empirical studies are the level of motor functioning, type and severity of the motor disability, intellectual status, educational level, additional sensory, speech and language impairments, and manual skills and age. The influence of gender as a factor varied from study to study. The predominant factors related to the regional and local social communities which have a direct or an indirect impact on the participation of children with CP are the individual and institutional attitudes, accessibility, architectural barriers, transport, family support, social community support, place of residence and the economic power of the social community.

The aim of this paper is to present studies which had the identification of the predictors and determination of the significance, nature and extent of social participation of children with CP in school environment as a focus of their research. We will proceed by reviewing the literature and systematizing the knowledge of this area through defining the predictors and determinants of participation and by analyzing the presented studies. Further work based on this paper may focus on designing guidelines for the promotion of the social participation of children with CP and the implementation of this summarized knowledge in the practical work in inclusive conditions.

Methods

The basic search was conducted via Google Scholar – Brief Search. The following key words were used: children with cerebral palsy, young with cerebral palsy, social participation, school participation, inclusion, social integration, accessibility, barriers, school environment, and social environment. The search was limited to the studies published in the period from January 1st 1990 to May 31st 2011. Also, the search was conducted by the well-known authors and we used the references from the published papers that were found and selected for this study on the basis of the previous search. The insight into the available literature was carried out by a further search of six electronic databases (EBSCOhost, Wiley Interscience, Cambridge University Press, Free Medical), available through KoBSON, and through the search of Informa Healthcare Services. The available printed sources were also used. The search was completed in June 2011. As the result of a comprehensive search, a total of 168 studies was collected and examined, out of which 39 met the preliminary inclusion criteria and had the social participation in the focus of their studies and as a target had a group of children and/or adolescents with CP. We excluded 129 studies on the basis of the following criteria: they were not published in English, Serbian or Croatian languages, the subjects of their studies were not children and/or adolescents with CP, physical disability and its effects on health and functional abilities were in the focus of their research, they were published before 1990 (because the problem of social participation was not considered in the inclusive aspect by the international and domestic scientific community until then), they had an inadequate methodological design or presentation of results. After that, out of the remaining 38 preliminary relevant studies, 30 of them were excluded because they did not meet the key criteria for defining the predictors of school participation. Only the remaining 8 studies were analyzed for the purpose of this study. Their samples or subsamples were made up of children with CP, and their aims were to define the predictors of school participation.

Results

Few studies were aimed at identifying the factors that could pre-determine or predict social participation of children with CP within the school environment. Table 1 shows

the summary of studies that investigated school participation of children with cerebral palsy according to their research design, the objective and focus of each study, the subjects included (number, diagnosis, age), and the main outcome measures used.

Mancini, Coster, Trombly, and Heeren (2000) conducted their research in 40 states in the United States. The objective of their study was to define the overall participation and to identify the predictors of participation in school activities of 341 children with various disabling conditions, including CP. The average age of children was 9.02 years (± 2.2). All children attended public elementary schools. The first and the third part of the *School Function Assessment* scale (SFA; Coster et al., 1998) were used. They were designed to evaluate and measure the performance of the specific functional activities that were the basis for the inclusion of children in the academic and social aspects at elementary school level. That enabled researchers to study the abilities of pupils with various types and severity levels of disabilities in order to create individual educational programmes for them. In this study the general participation of each child was determined by summing up the measured participation in six different contexts (transportation, transitions, activities in the classroom, cafeteria, bathroom, and on playground). After that, subjects were dichotomized into full ($n=117$) and limited ($n=224$) participation categories. The authors have distinguished three models that included predictors of participation as key variables: the ability to dress, fine and gross motor skills and the level of impairment (but not the type of impairment). Full participation was predicted by a combination of physical and cognitive-behavioral variables, while limited participation was primarily predicted on the basis of the information gathered concerning children's physical capabilities. Furthermore, the authors have emphasized that the results underscore the relative utility of comparing functional abilities with the impairment information to predict the outcomes of the social participation. They have also stressed that the suggested models should be the subject of further research and the framework of the reactions and efforts of the professional community.

Following their previous research, Mancini and Coster (2004) published more results which indicated particular functional predictors of social participation of children with disabilities. The study included 266 subjects aged 4-18, out of which 77 had motor disorders, including CP. General participation in different school environments and success in carrying out specific activities in a given environment, i.e. physical and cognitive-behavioral tasks as individual variables, were also identified by the first and third part of the SFA scale. According to the results, each one of the six different school contexts had a different model of the statistically significant variables and functional tasks whose successful performance pointed out the possibility of future social participation in a given context. Also, the number of these predictors varied in each of the models (from 2 to 5). The results confirmed that none of the individual variables alone could become a clear predictor of participation in each of the contexts. They need to be interwoven in a given model. Each one of the defined models presented a

combination of physical and cognitive-behavioral predictors of social participation. This indicates that successful social participation in school environment requires the ability to perform complex tasks and activities that integrate the capabilities in both domains. For example, in order to participate in a certain school context, a child needs to meet the requirements of both physical and cognitive-behavioral tasks typical of each of these contexts. Although cognitive and behavioral activities in the settings of special and regular classrooms receive most attention, the results indicate that a successful participation in these contexts also demands significant physical requirements. This finding is important because it suggests that children with specific disability types may still be able to meet some of the important requirements for participation in these contexts. Also, the findings suggest that children should have skills in both domains, regardless of the domain of the primary impairment, in order to allow for a more accurate prediction of the participation outcomes. Further on, this suggests that children with a combination of various impairments will probably have more difficulties in social participation in different settings when compared to children with only one type of disability. This conclusion confirms that while assessing a child's physical and cognitive-behavioral skills, the environment in which the child operates should be taken into account, including the barriers that hinder or prevent full social participation and the requirements set to the child by the environment.

Schenker, Coster, and Parush (2005a) conducted a study with the purpose of defining personal and environmental factors that may indicate the level of social participation achieved by the children with CP within the elementary inclusive school context compared to the level of achievements of their typical peers and their peers with CP in self-contained classes. The aim of this study was also to explore the relationships between the achieved level of social participation and the estimated level of functional activity within a given environment, and to identify the predictors of participation at various school activities. The authors have defined participation as a pupil's active engagement in the activities that are specific for certain situations in school, and the performance of functional activities as a pupil's ability to initiate and complete certain specific functional school relevant activities. The study included 248 subjects aged 6-13. The first group consisted of 100 fully included (FI) pupils with CP while the control group consisted of 100 typical (non-disabled) pupils. The third group consisted of 48 pupils with CP in the self-contained (SC) classes (special-classroom). There were no statistically significant differences between these groups according to their age and gender. For the purpose of determining the level of social participation, general and specific, in six different school contexts and the levels of functionality by a series of physical and cognitive-behavioral tasks, the first and the third part of the SFA scale were used. As expected, the highest level of participation was found among the typical pupils, and the lowest one among the pupils with CP in SC classes. Physical activity performance was identified as the most significant predictor of social participation for both groups of children with CP, while the cognitive-behavioral factor was noted

as the most significant predictor in the control group. Given that the group of children with CP in SC classes showed the highest level of impairment, it can be concluded that increased levels of participation may be more strongly associated with the decreased levels of the severity of impairment.

As a continuation of their previous research (Schenker, Coster, & Parush, 2005a), Schenker, Coster, and Parush (2005b) studied 148 subjects with CP (87 boys and 61 girls), aged 6-14 (average 9 years, 8 months; SD 1 year, 11 months). Their sample consisted of 100 FI pupils and 48 SC pupils of general elementary schools in Israel. Their social participation and activity performance (motor, cognitive and behavioral), estimated according to the SFA scale, varied in relation to the diagnosed type of CP, the level of impairment according to *the Gross Motor Function Classification System* (GMFCS), and the presence of additional neuroimpairments. Physical activity performance made some difference in social participation between children with different types of CP and different levels of motor impairment. According to these data, a higher level of motor impairment and the presence of some additional neuroimpairments (speech and language impairments and learning disability) may be significant predictors of participation and activity performance. Statistically significant differences were found for FI children with CP with speech and language impairments and those with learning disabilities in the SC group. According to the authors, additional speech and language impairments were significant limiting factors of social participation of children with CP.

In the next study, Schenker, Coster, and Parush (2006) set up a research aimed at determining differences in the levels of participation achieved by the FI pupils with CP as compared to pupils with CP in SC classes in general elementary schools in Israel. The aims of this study were also to examine the differences in the task supports provided to these two groups, the interrelationships between the necessary assistance and/or adaptation, and the differential impact of the physical task supports opposite to the cognitive-behavioral task support on the estimated level of social participation. A total of 148 participants were divided into two groups: 100 FI pupils with CP and 48 pupils with CP from SC classes. No significant statistical differences were found between these groups according to their age and gender. For assessing the level of participation, general and specific, across six major school activity contexts, the first part of the SFA scale was used, and the second part of the same scale was used for assessing the extent of supports provided in the form of assistance (by adults) and adaptation (modifications of the environment, teaching aids and equipment and/or the curriculum). Statistically significant differences between these two groups of subjects were detected on all scales, i.e. between physical and cognitive-behavioral assistance and adaptation. The results confirmed that the higher level of support was provided to the group of pupils with CP in SC classes in comparison to FI pupils with CP. Also, physical support was provided significantly more often than the cognitive-behavioral support to the pupils in both study groups. Further analysis of

the collected data suggested that the provision of physical support, rather than the environmental modification or adaptation, reduces the opportunities for successful social participation of children with CP in SC classes. The adaptation of the teaching aids and equipment as well as the provision of greater support in the cognitive and behavioral activities such as supplementing or replacing physical assistance provided by adults, could create better opportunities for a more active and diverse social participation of children with CP, thus allowing for their successful academic and social achievement. The importance of this research is in the validation of the impact which assistance and adaptation as well as the environmental factors have on the process of social participation of children with CP in a regular school environment, but also on determining their interrelationships.

The results of the study investigating personal and environmental factors as predictors of school participation conducted in the US by Simeonsson, Carlson, Huntington, McMillen, and Brent (2001) identified the pupils' age, ethnicity and level of impairment as key predictors. In this descriptive study a specially designed questionnaire *The National Survey of School Environments* (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001) was used on the data collected from 1180 teachers enquiring about the school environment, available activities and social participation of children with motor disabilities. Subjects were 5-18-year-old. The reduced level of social participation was observed in younger pupils of Hispanic origin and with a more severe level of impairment, while the gender of the subjects was not statistically significant. Also, the participation was reduced in smaller schools (with less than 150 pupils), and it was highest in schools with a large number of pupils (with more than 750 pupils).

Eriksson (2005) applied the adapted version of the questionnaire which Simeonsson et al. (2001) had used in their research. The questionnaire was adapted to the school system in Sweden, and unlike the original version, which was filled in by the teachers, the answers were given by the pupils with disabilities themselves. The study was descriptive and focused on investigating the relationship between the environmental factors and participation in school activities, on the impact of the general and specific environmental adaptation on school participation and on the way that personal assistance's engagement affects the participation in different school activities. No significant statistical differences were confirmed between any of the environmental factors and the given support and participation in school, except for the availability and school participation according to the pupils' own ratings.

According to the results, some specific environmental factors had a greater impact than the general environmental factors. Pupils' own ratings of availability were the strongest predictor of participation while the environmental factors estimated by others did not have strong statistical relations to pupils' participation. The personal assistances' support also had a positive effect on the pupils' assessment of availability, but at the same had a negative effect on the pupils' independence in school activities.

These results indicated the need to focus future studies on the latent potential of this population. The type of the disability, the level of impairment, and the number of disabilities (multiple disability) did not have a strong impact on school participation, which was confirmed during the same year in the survey conducted by Almqvist and Granlund (2005), also in Sweden. They found that the higher level of social participation of pupils with disabilities, including children with CP, is affected by a combination of different factors, where the more important factors are those which have a positive impact on participation than the content of each combination. As key predictors of school participation, the authors have highlighted positive relationships with teachers and peers and a higher level of independence.

Table 2 shows the summary of studies that investigated school participation of children with cerebral palsy according to their main findings, conclusions and basic recommendations for future scientific, professional and rehabilitation work.

Discussion

The presented literature review has shown that authors differ in their definitions of the predictors of social participation of children with CP. However, they all agree in one – that there is a complex relation between disability, participation and school environment, and that the extent of participation is directly dependent on the number of interrelated factors.

Participation was largely defined in six different contexts within the school environment. Several variables were responsible for full or limited participation in each of these environments and no variable by itself could function as a clear and sufficient predictor of the social participation of pupils with CP. The presented studies have found the most important predictors of participation to be the following: physical activity performance, the level of autonomy, relationships with teachers and peers, fine and gross motor skills, the ability to dress, the type of support provided, additional neuroimpairments, pupils' own assessment of availability, age, ethnicity, school size, assistance and adaptations. All predictors were classified either into the group of personal or the group of environmental factors.

It is interesting that in terms of the level of motor impairment as the predictor of social participation of children with CP, we find mismatching results in the studies from the U.S., Israel and Sweden. In American and Israeli studies high levels of participation were in a strong correlation with the lower level of impairment, while the Swedish studies showed that type, level and number of disabilities were not significant predictors of the extent of school participation. We believe that this difference is the

Note for Table 1. SFA = The School Function Assessment Scale, Part 1 = Participation, Part 2 = Task Supports, Part 3 = Activity Performance, GMFCS = The Gross Motor Function Classification System Scale, Mixed = Various disabling conditions and severity levels including Cerebral Palsy, CP = Cerebral Palsy, FI = Fully Included, SC = Special-Classroom, NSSE = The National Survey of School Environments, SE = Special-Education.

Table 1. Summary of studies that investigated school participation of children with cerebral palsy – research design

| Study | Country | Objective | Focus | n | Dg | Age | Measures |
|------------------------------|-----------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------|-----------------------------------------------------------|-------------------------|--------------------|--------------------------------|
| Mancini et al. (2000) | USA and Puerto Rico | To identify predictors of participation in school activities. | Personal factors and impairment | 341 | Mixed | 9.02 (\pm 2.2) | SFA – Part 1 and Part 3 |
| Mancini and Coster (2004) | USA, Puerto Rico and Canada | To identify functional predictors of school participation. | Personal factors | 266 | Mixed (CP $n \leq 77$) | 4-18 | SFA – Part 1 and Part 3 |
| Schenker et al. (2005a) | Israel | To explore the relationship between the levels of participation and activity performance, to identify predictors of participation in various school activities. | Personal and environmental factors | 248 pupils: 100 FI, 48 SC, 100 typical | CP | 6-13 | SFA – Part 1 and Part 3 |
| Schenker et al. (2005b) | Israel | To examine the relationship between activity performance and the level of participation, according to the type of the additional neuroimpairment and the level of gross motor impairment. | Personal and environmental factors | 148 pupils: 100 FI, 48 SC | CP | 6-13 | SFA – Part 1 and Part 3; GMFCS |
| Schenker et al. (2006) | Israel | To examine the differences in the level of participation and task supports, the interrelationships between the assistance and adaptation provided and the differential impact of physical and cognitive-behavioural task supports on participation. | Personal and environmental factors | 148 pupils: 100 FI, 48 SC | CP | 6-13 | SFA – Part 1 and Part 2 |
| Simeonsson et al. (2001) | USA | To examine the nature and extent of school participation in the context of the physical, social and psychological features of school environment. | Personal and environmental factors | 1 180 | Mixed | 5-18 | NSSE (56-items) |
| Eriksson (2005) | Sweden | To investigate the interrelationship between the environmental factors (community, general school and individual support) and participation in school activities. | Environmental factors | 509 pupils, 460 teachers, 105 SE counsellors | Mixed | 7-12, 13-17, adult | NSSE (adapted version) |
| Almqvist and Granlund (2005) | Sweden | To identify the patterns of the interrelated positive subject and environmental factors related to school participation. | Environmental and personal factors | 431 pupils, 103 SE counsellors, 414 parents, 419 teachers | Mixed | 7-12, 13-17, adult | NSSE (adapted version) |

Table 2. Summary of studies that investigated school participation of children with cerebral palsy – findings, conclusions and recommendations

| Study | Findings and Conclusion | Recommendations |
|---------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Mancini et al. (2000) | The predictors of limited participation (n=224) – information about physical capabilities (clothing management, fine and gross motor factors). The predictors of full participation (n=117) – a combination of physical and cognitive-behavioral variables (clothing, use of social conventions, motor and social-behavioural factors). The severity of impairment (not type), predicted participation. | To consider the relative utility of comparing functional performance with impairment information only while predicting school participation. |
| Mancini and Coster (2004) | A different set of predictors (from 2 to 5 variables) for each school context, the success of participation associated with the performance on both physical and cognitive-behavioural activities. Some aspects of function were context-specific. | To assess both physical and cognitive-behavioural performance of a child across various school contexts with different functional skills demands and different physical and social barriers. |
| Schenker et al. (2005a) | Significant differences ($p < 0.0001$) in the levels of participation. The limitations of activity performance had an impact on participation. Physical activity was a significant predictor in both FI and SC groups ($p < 0.0001$). The cognitive-behavioural factor was a significant predictor in the typical group ($p < 0.0001$). | The importance of providing rehabilitative interventions for the purpose of removing the existing physical and social barriers within the inclusive school environment. |
| Schenker et al. (2005b) | Significant differences in the levels of participation and activity performance (motor and cognitive-behavioural) between different types of CP and GMFCS levels, mainly due to differences in physical activity performance. The levels of participation and activity performance decrease as the motor disability and/or additional neuroimpairments increase. | The importance of communication in the facilitation of school participation. Additional neuroimpairments (speech and language impairments and learning disability) were significantly limiting factors. |
| Schenker et al. (2006) | The participation of the FI group was significantly greater than that of the SC group. Statistically significant differences ($p < 0.0001$) were found on all scales (physical and cognitive-behavioural assistance and adaptations). Significantly greater supports were provided to the SC group. Physical task supports provided to both groups were significantly greater than the cognitive-behavioural task supports. | The provision of assistance serves as a barrier to participation to some extent, decreasing the opportunities of full participation. The increased use of adaptations and cognitive-behavioural task supports might enhance participation by reducing the need for assistance. |
| Simeonsson et al. (2001) | Key predictors of school participation: age, ethnicity and impairment severity as personal factors; school location and the number of pupils as environmental factors. | Different aspects of functioning, activity performance, and participation were essential during school life in elementary, middle and high schools. |

Note for Table 2. GMFCS = The Gross Motor Function Classification System level, CP = Cerebral Palsy, FI = Fully Included, SC = Special Classroom.

| Study | Findings and Conclusion | Recommendations |
|------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Eriksson (2005) | Slight increase in participation across the three age groups. No statistically significant relationship between participation and any environmental factors or support provided. Pupils' own perceptions of their individual environment were related to participation. The support provided was related more to the type and number of disabilities than to participation with a positive effect on the availability of activity but a negative effect on pupil's autonomy, rated by the pupils themselves. | The environmental factors affect pupils' participation. However, the ratings carried out by the pupils and the information on the available activities and types of activities they are active in are necessary as a basis for the intervention focused on participation. |
| Almqvist and Granlund (2005) | A higher degree of participation was characterized by higher scores in autonomy, the perceived interaction with peers and teachers, the internal locus of control and positive interactions with others rather than by the environmental factors. Gender, and type, level and number of disabilities had no significant effect on participation. | Participation is better predicted by the patterns of interrelated positive subject and environmental factors than by any other single factor. |

result of the more objectively defined predictors in American and Israeli studies than in the Swedish studies, where the predictors were defined on the basis of pupils' self-assessments. Therefore, we tend to believe that a higher level of motor impairment and a number of present disabilities present the risk factors for the full extent of participation. On the other hand, the type of the disability might present the risk factor, given that the level of functional activity performance is more important in terms of social competence than the disability type.

We find it important to emphasize that the aforementioned group of predictors is nothing compared to the synthesized data on predictors that do not appear in the same frequency in all the presented studies. Physical functional activity performance presents a dominating factor in determining the participation of children with CP in the school environment. Given that the importance of this factor is recognized in all studies, we tend to generalize and highlight it as the factor that determines the extent of participation.

The type of support provided has proven to be both a protective factor and a risk factor at the same time. Physical task support is a protective factor in one area, but also a risk factor for the participation in some other areas of functioning in the school environment (such as autonomy). Therefore, it is a predictor of limited participation. On the other hand, cognitive-behavioral task support is proven to be only the protective factor and the predictor of full participation.

Regardless of the complexity of the problem and the difficulty in identifying individual predictors, the importance of both personal and environmental factors and their interactions is recognized, as well as the impact of personal characteristics of children with CP in terms of their physical or motor skills and cognitive-behavioural performance.

Conclusions

Eight studies designed with the objective of identifying the predictors of social participation of children with CP are presented in this paper. Two studies focus on the personal factors that affect the social participation of children with CP, one on the environmental factors, while the remaining five focus on defining both personal and environmental factors. The samples of the first three studies comprise only children with CP, while in the remaining five studies children with CP are a subsample of children with motor disorders or various types of disabilities. As a result, the main limitation of the present study is directly related to the limitations of the presented studies. This is primarily due to the small number of studies focusing on this topic and the fact that the latter five studies have investigated children with various types of disabilities as their sample subjects. Therefore, the results related to this population only could not be isolated but were reviewed as part of the complete sample. On the other hand, it is a fact that only two basic measurement instruments were used to define the predictors in the presented studies: *the School Function Assessment (SFA) – Part 1 (Participation), Part 2 (Task Supports) and Part 3 (Activity Performance)* in the five studies focusing on children with various types of disabilities, and *The National Survey of School Environments* (original and adapted version) in the three studies focusing on children with CP. Thus, a qualitative synthesis of the data from different studies is provided.

The results and conclusions presented in the studies above, despite the fact that they refer to the school systems and educational milieus specific to the country of origin, lead to the conclusion that school participation is an important factor of biopsychosocial development of each child allowing him/her to develop into a healthy, independent individual and an active member of the society. Participation in everyday activities (at school and the extracurricular ones) is a good basis for developing social skills and social networks of support for each child, while the engagement in the activities of reduced quality and lower frequency may have a negative impact on the establishment of social relationships, accommodation and the quality of life.

However, there is not enough synthesized data available to allow for a valid generalization so that the functional activity and social participation of children with CP can be explained only by the combined impact of physical and cognitive-behavioral variables as well as by the interaction of the personal and environmental factors. The fact is that the physical variables are only significant in a partial, limited participation, and that cognitive-behavioral variables are necessary for realizing the participation to its full extent. As for the impact of the personal and environmental factors, the importance of the environmental factors as facilitators of participation is more emphasized than the importance of the personal factors. Nevertheless, we believe that the importance of personal factors for the participation of children with CP is excluded. Therefore, the creation of professional programmes aimed at the environmental factors only could result in the insufficient engagement in enhancing the personal performance of each child. Accordingly, the strengthening of children's personal capacity and

simultaneous impact on the environmental factors would constitute the foundation of a comprehensive action oriented at the full social inclusion of these children.

The key steps in the professional intervention include the development of strategies which will enable children with CP to take full advantage of the possibilities provided by everyday school activities in terms of active social participation. Moreover, school staff need to be educated in creating situations in which children are involved as active participants, with the inevitable reciprocal interactions with their typical peers, and with the aim of achieving full social participation. Also, we recommend that all school activities be structured and planned in such a way that their implementation excludes any form of discrimination, considering that social integration is fully achieved through participation in joint activities, by providing affirmative experiences and improving the social skills of children with CP.

Finally, on the basis of the knowledge obtained by means of the conducted literature review and analysis, we can conclude that this area of scientific and professional interest is still not well researched. Further studies need to help provide a more adequate identification of predictors, protective factors and risk factors of the participation of children with CP, thus providing a complete definition and generalization of the models of variables. This would enable the creation of school environments as contexts in which children with CP could acquire academic skills and social norms in the same manner and to the same extent as their peers as well as form their own personality and gain social competence. Such an approach would allow them to transfer all the acquired skills from an inclusive school environment to all forms of social life, thus realizing the ultimate goal of both education and rehabilitation of children with CP – participation and full social integration.

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Prediktori socijalne percepcije djece sa cerebralnom paralizom u školskom okruženju

Sažetak

Cilj rada je da se, revijalnim pregledom literature, izdvoje istraživanja koja su u svoj fokus postavila identificiranje prediktora i utvrđivanje značenja, prirode i obujma socijalne participacije djece s cerebralnom paralizom u školskom okruženju i da se, analizom izdvojenih studija, sistematiziraju saznanja iz ovog područja, što bi rezultiralo kreiranjem smjernica za unaprjeđenje društvenog sudjelovanja ove djece i implementacijom ovako sumiranih saznanja u praktičan rad u inkluzivnim uvjetima.

Dobiveni rezultati upućuju na zaključak da postoji složen odnos između onesposobljenosti, participacije i školske sredine i da se prediktori ne mogu izdvojiti i promatrati kao izolirani entiteti, već isključivo kao kombinirani modeli interaktivnih fizičkih i kognitivno-bihevioralnih varijabli.

Ključni koraci u stručnom interveniranju podrazumjevaju razvijanje strategija kojima će se omogućiti djeci s cerebralnom paralizom da u punoj mjeri iskoriste mogućnosti koje svakodnevne školske aktivnosti pružaju u pogledu aktivnog socijalnog uključivanja.

Ključne riječi: socijalna integracija, onesposobljenost, vršnjaci.

Uvod

Puno društveno sudjelovanje djece s cerebralnom paralizom (u daljnjem tekstu: CP) podrazumijeva uključivanje u sve aktivnosti u obiteljskom, vršnjačkom, školskom i izvanškolskom okruženju u istom obujmu i istoj mjeri u kojoj je to slučaj s djecom urednog razvoja, odnosno djecom bez teškoća. Milićević, Potić, i Trgovčević (2011) navode da su mnogobrojna istraživanja pokazala da je participacija u svakodnevnim aktivnostima od ključnog značenja za kvalitetu života djece s CP i da predstavlja nezamjenljiv prediktor adekvatnog razvoja.

Bez obzira na dostupnost saznanja o značaju socijalne participacije u najranijoj dobi i tijekom djetinjstva, postoji značajan rizik da djeca s CP budu izuzeta iz uobičajenih aktivnosti u okviru obitelji i/ili zajednice (King i sur., 2003), što neminovno vodi u

socijalnu isključenost. Trgovčević i Kljajić (2011) navode da društvo utječe na razvoj pojedinca tokom djetinjstva i da ima veliki utjecaj tokom cijelog ljudskog života, a da je za proces socijalnog uključivanja podjednako važna uloga svih čimbenika: samog pojedinca, obitelji, škole i vršnjaka, užeg i šireg društvenog okruženja, kao i cjelokupne socijalne politike društva u kome pojedinac egzistira. Taj problem dodatno dobiva na značaju kada se u obzir uzme činjenica da s povećanjem starosne dobi istodobno dolaze i sve veći društveni i okolinski zahtjevi koji nameću potrebu za promjenama u načinima i obujmu participacije svakog pojedinca u svim segmentima života i u svim društvenim aktivnostima kao osnovnog preduvjeta socijalne integracije (Milićević i sur., 2011).

Različita su mišljenja stručne i znanstvene javnosti koje su determinante presudne za (ne)ostvarivanje socijalne participacije djece s CP, generalno ili u pojedinim područjima socijalnog funkcioniranja. Tako Ilić i Nikolić (2001) smatraju da proces socijalne integracije osoba s posljedicama CP otežavaju ili onemogućavaju teškoće u motoričkom funkcioniranju, dok Rapaić i Nedović (2011) navode da velika varijabilnost motorne disfunkcije u smislu vrste ispada i intenziteta, kao i česta kombinacija s intelektualnim, osjetilno-perceptivnim i govornim poteškoćama, čine ovu populaciju djece i mladih veoma nepodesnom za planiranje uniformnih sistemskih rješenja, bilo da je riječ o edukativnim, rehabilitacijskim ili socijalnim programima.

Milićević i Potić (2011) su, prihvaćajući rezultate ekstenzivnog pregleda literature, zaključili da razumjevanje složenosti i raznolikosti participacije djece s CP, različite dobi i u različitim okruženjima, zahtijeva širi fokus od samog utvrđivanja njihovih individualnih performansi u pojedinim aktivnostima i aspektima osobnog i društvenog života, a da je razina ostvarene socijalne participacije djece s CP direktno zavisna od individualnih determinanti, odnosno onih koje su vezane za samo dijete i okolinskih, odnosno čimbenika iz socio-kulturnog okruženja, kao i od njihove interakcije. Autori su našli da se, kao najfrekventniji u empirijskim studijama, od individualnih čimbenika koji determiniraju socijalnu participaciju djece s CP izdavaju razina motoričkog funkcioniranja, motoričke disfunkcije u smislu ispada i intenziteta, intelektualni status, razina obrazovanja, prisutnost senzornih i govorno-jezičnih teškoća, manualne sposobnosti i dob, dok je utjecaj spola kao čimbenika varirao od studije do studije. Od činilaca iz užeg i šireg okruženja, bilo da su oni fizički, društveni, politički ili institucionalni, a koji imaju direktan ili indirektan utjecaj na socijalno uključivanje djece s CP, predominantni su individualni i institucionalni stavovi, pristupačnost, arhitektonske barijere, mogućnost transporta, podrška obitelji, podrška socijalnog okruženja, mjesto stanovanja i ekonomska moć socijalnog okruženja.

Cilj ovog rada je da se, revijalnim pregledom literature, izdvoje istraživanja koja su u svoj istraživački fokus postavila identificiranje prediktora i utvrđivanje značaja, prirode i obujma socijalne participacije djece s CP u školskom okruženju, i da se, analizom izdvojenih studija, sistematiziraju saznanja iz ovog područja kroz definiranje

prediktora i determinanti participacije, što bi rezultiralo kreiranjem smjernica za unapređenje socijalne participacije djece s CP i implementacijom ovako sumiranih saznanja u praktičan rad u inkluzivnim uvjetima.

Metode

Osnovna pretraga obavljena je preko pretraživača Google Scholar – Brief Search i tom prilikom korištene su sljedeće ključne riječi: children with cerebral palsy, young with cerebral palsy, social participation, school participation, inclusion, social integration, accessibility, barriers, school environment, social environment. Pretraga je ograničena na objavljena istraživanja u periodu od 1. siječnja 1990. godine do 31. svibnja 2010. godine. Također, pretraga je obavljena i prema poznatim autorima, a upotrijebljavane su i reference iz radova koji su pronađeni i izdvojeni za potrebe ovog istraživanja na osnovi prethodne pretrage. Uvid u dostupnu literaturu izvršen je daljim pregledom elektronskih baza podataka (EBSCOhost, Wiley Interscience, Cambridge University Press, Free Medical), dostupnih preko KOBSON-a, kao i pretragom Informa Healthcare servisa. Korištena je i literatura dostupna u tiskanoj verziji. Pretraga je završena u lipnju 2011. godine. Kao rezultat sveobuhvatne pretrage prikupljeno je i pregledano ukupno 168 studija od kojih je 39 ispunilo preliminarnu kriterije sudjelovanja, odnosno onih koje su za cilj istraživanja imale socijalnu participaciju, a za ciljnu grupu djecu i/ili adolescente s CP. Ukupno 129 studija je isključeno na osnovi sljedećih kriterija: nisu objavljene na engleskom, srpskom i hrvatskom jeziku; za ispitanike nisu imale djecu i/ili adolescente s CP; u svom istraživačkom fokusu imale su samo utjecaj tjelesnoga oštećenja i njegove posljedice na zdravstveno stanje i funkcionalne sposobnosti; objavljene su prije 1990. godine (iz razloga što se u međunarodnoj i domaćoj znanstvenoj javnosti problematika socijalne participacije do tog perioda nije razmatrala s inkluzivnog aspekta); neadekvatan metodološki dizajn ili prikaz rezultata. Nakon toga, od preostalih 38 preliminarno relevantnih istraživanja, isključeno je 30 studija koje nisu zadovoljavale ključni kriterij definiranja prediktora participacije u školskom okruženju, tako da je preostalo 8 studija koje su za uzorak ili poduzorak imale djecu s CP, a za cilj definiranje prediktora socijalne participacije u inkluzivnom školskom okruženju i one su analizirane za potrebe ovog rada.

Rezultati

Malobrojna istraživanja bila su fokusirana na utvrđivanje čimbenika koji bi mogli unaprijed determinirati, odnosno predvidjeti socijalnu participaciju djece s CP u školskom okruženju. U Tablici 1 dat je prikaz izdvojenih istraživanja socijalne participacije djece s cerebralnom paralizom u školskom okruženju prema metodološkom dizajnu istraživanja, odnosno prema cilju i fokusu istraživanja, prema ispitanicima uključenim u istraživanje (broj ispitanika, utvrđene dijagnoze i uzrast), kao i prema glavnim korištenim mjernim instrumentima.

Mancini, Coster, Trombly, i Heeren (2000) su svojim istraživanjem provedenim u SAD, u 40 različitim državama, definirali sveukupnu participaciju 341 ispitanika prosječne

dobi od 9.02 godina (± 2.2). Svi ispitanici su pohađali državne osnovne škole. Koristili su prvi i treći dio skale *The School Function Assessment* (SFA; Coster et al., 1998) koja je dizajnirana da procijeni i izmjeri izvođenje pojedinih funkcionalnih aktivnosti koje su osnova uključivanja u akademske i socijalne aspekte na nivou programa osnovnih škola i na taj način omogućiti stručnjacima uvid u sposobnosti učenika s različitim oblicima i stupnjevima onesposobljenosti, a samim tim i izradu individualnih obrazovnih programa. U navedenom istraživanju, sveukupno sudjelovanje svakog djeteta posebno utvrđeno je sumiranjem izmjerenih participacija u šest različitih okruženja (transport do i od škole, kretanje između satova, u učionici, u školskoj kuhinji, u toaletu, na igralištu ili za vrijeme odmora), a zatim su napravljene dvije podgrupe ispitanika, pri čemu su jednu činili ispitanici s punom ($n=117$), a drugu ispitanici s ograničenom participacijom ($n=224$). Autori su postavili tri modela koja uključuju prediktore participacije kao ključne varijable: sposobnost oblačenja, fine i grube motorne sposobnosti i stupanj oštećenja (ali ne i tip oštećenja). Zaključili su da punu participaciju određuje kombinacija fizičkih i kognitivno-bihevioralnih varijabli, dok na ograničenu participaciju prvenstveno upućuju podaci o djetetovim fizičkim sposobnostima. Autori su dalje istakli da rezultati ukazuju na relativnu korisnost povezivanja funkcionalnih sposobnosti s podacima o samom oštećenju s ciljem predviđanja ishoda socijalnog uključivanja, kao i da bi predloženi modeli trebali biti predmet daljih istraživanja i okvir reagiranja stručne javnosti.

Nadovezujući se na prethodno istraživanje, Mancini i Coster (2004) objavljuju dalje rezultate koji su ukazali na pojedine funkcionalne prediktore socijalne participacije djece s teškoćama u razvoju. Istraživanjem je bilo obuhvaćeno 266 ispitanika uzrasta 4-18 godina od kojih je 77 bilo s motoričkim poremećajima, uključujući i CP. Sveukupna participacija u različitim školskim okruženjima i uspješnost obavljanja konkretnih aktivnosti u datim okruženjima, odnosno fizičkih i kognitivno-bihevioralnih zadataka kao pojedinačnih varijabli, bili su također utvrđeni prema prvom i trećem dijelu skale SFA. Svako od šest različitih školskih okruženja, prema dobivenim rezultatima, imalo je drugačiji model statistički značajnih varijabli, odnosno funkcionalnih zadataka čija je uspješnost izvršavanja ukazala na mogućnost budućeg socijalnog uključivanja u dato okruženje. Također, broj ovih prediktora je varirao za svaki od modela (od dva do pet). Rezultati su potvrdili da nijedna varijabla sama po sebi ne može biti jasan prediktor participacije u svakom od okruženja, već isključivo u sklopu datog modela. Zajedničko za svaki od utvrđenih modela jest da predstavlja kombinaciju fizičkih i kognitivno-bihevioralnih prediktora participacije što upućuje na zaključak da uspješno socijalno uključivanje u školskom okruženju zahtjeva sposobnost izvođenja kompleksnih zadataka i aktivnosti koje u sebi integriraju sposobnosti iz obje domene. Na primjer, kako bi moglo participirati u pojedinim okruženjima, dijete treba ispuniti zahtjeve postavljene i u fizičkim i u kognitivno-bihevioralnim zadacima tipičnim za svaki od ovih konteksta. Iako se najviše pažnje posvećuje kognitivnim i bihevioralnim aktivnostima u okviru okruženja specijalnog i redovnog

odeljenja, rezultati ukazuju na značajne fizičke zahtjeve koje podrazumijeva uspješna participacija u ovim okruženjima. Ovakav nalaz je važan jer ukazuje na to da bi djeca sa specifičnom vrstom oštećenja i dalje bila u mogućnosti ispuniti neke od važnijih uvjeta za participaciju u različitim sredinama. Također, nalaz ukazuje na potrebu da se posjeduju sposobnosti u oba domena, bez obzira u kojoj je domeni primarno oštećenje, a u cilju boljeg predviđanja ishoda participacije. To dalje može ukazivati na to da će djeca s višestrukim teškoćama, u odnosu na onu djecu sa samo jednim tipom oštećenja, najvjerojatnije imati poteškoća u socijalnom uključivanju u okviru različitih okruženja. Ovakav zaključak je potvrdio potrebu da se pri procjeni djetetovih fizičkih i kognitivno-bihevioralnih sposobnosti uzme u obzir i okruženje u kome ono funkcionira, što podrazumijeva kako barijere koje otežavaju ili onemogućavaju potpuno socijalno uključivanje tako i zahtjeve koje to okruženje djetetu postavlja.

Schenker, Coster, i Parush (2005a) su fokus svog istraživanja usmjerili k definiranju osobnih i okolinskih čimbenika koji mogu ukazati na razinu socijalne participacije koju su djeca s CP ostvarila u inkluzivnom školskom okruženju u odnosu na onu razinu koju postižu njihovi vršnjaci iz redovne populacije i njihovi vršnjaci s CP u okviru posebnih odjela u redovnim osnovnim školama. Cilj ovog istraživanja je bilo utvrđivanje odnosa između postignute razine socijalne participacije i procjenjene razine funkcionalnih aktivnosti u datim okruženjima, kao i identificiranje prediktora participacije u različitim školskim aktivnostima. Autori su definirali participaciju kao aktivno uključivanje učenika u one aktivnosti koje su karakteristične za određene situacije u njihovoj školi, a izvršavanje funkcionalnih aktivnosti kao sposobnost učenika da započne i dovrši pojedine specifične školske funkcionalne aktivnosti grupirane prema općim zadacima. Istraživanjem je bilo obuhvaćeno 248 ispitanika dobi 6-13 godina. Prvu grupu je činilo 100 učenika s CP koji su pohađali nastavu u redovnim inkluzivnim odeljenjima, dok je kontrolnu grupu činilo 100 njihovih vršnjaka iz redovne populacije. Treću grupu je činilo 48 ispitanika s CP koji su nastavu pohađali u posebnim odjelima redovnih osnovnih škola. Grupe su bile statistički ujednačene prema dobi i spolu. Za utvrđivanje postignute razine participacije, sveukupne i one u okviru šest različitih školskih okruženja, kao i razine funkcionalnosti, nizom fizičkih i kognitivno-bihevioralnih zadataka, korišteni su prvi i treći dio skale SFA. Prema očekivanjima, najviša razina sudjelovanja zabilježena je u grupi učenika iz redovne populacije, a najniža u grupi učenika s CP koji su pohađali nastavu u posebnim odjelima pri redovnim školama. Fizička aktivnost se pokazala kao značajan pokazatelj participacije obje grupe djece s CP, dok je kognitivno-bihevioralni čimbenik zabilježen kao najznačajniji prediktor u kontrolnoj grupi. S obzirom na to da je u grupi djece s CP koja pohađaju nastavu u posebnim odjelima pri redovnim školama zabilježen najteži stupanj oštećenja, može se zaključiti da su više razine participacije u jakoj vezi s nižim stupnjem oštećenja.

Nastavljajući prethodno istraživanje (Schenker, Coster, & Parush, 2005a), Schenker, Coster, i Parush (2005b) su istraživanjem obuhvatili 148 ispitanika s CP (87 dječaka

i 61 djevojčica), dobi od 6 do 14 godina (prosječni uzrast 9 god. 8 mjes., SD 1 god. 11 mjes.), od kojih je njih 100 bilo obuhvaćeno punom inkluzijom, a 48 je pohađalo posebne odjele u redovnim školama u Izraelu. Participacija i izvođenje aktivnosti (motornih, kognitivnih i biheviornalnih), procijenjeni skalom SFA, varirali su prema dijagnosticiranom tipu CP, razini oštećenja utvrđenom prema skali *The Gross Motor Function Classification System* (GMFCS) i prisutnosti dodatnih neuroloških oštećenja. Izvođenje fizičkih aktivnosti je djelomično činilo razliku u participaciji između djece s različitim tipovima CP i različitim stupnjevima motornog oštećenja. U uvjetima redovnog školskog okruženja, prema tim podatcima, viši stupanj motoričkog oštećenja i prisutnost nekog od pratećih neuroloških oštećenja (poremećaji govora i jezika, poremećaji učenja) mogu biti značajni prediktori participacije i uspješnosti pri izvođenju određenih aktivnosti. Statistički značajne razlike potvrđene su između učenika s CP koji su pohađali nastavu u redovnim inkluzivnim odjelima, a kod kojih je utvrđena prisutnost govorno-jezičkih teškoća i učenika s CP koji su pohađali posebne odjele, a kod kojih je utvrđena prisutnost teškoća u učenju. Prema mišljenju autora (Schenker, Coster, & Parush, 2005b), prisutnost dodatnih govorno-jezičkih teškoća predstavlja limitirajući čimbenik socijalne participacije djece s CP.

U svojoj sljedećoj studiji Schenker, Coster i Parush (2006) postavili su za cilj istraživanja utvrđivanje razlika u razinama participacije koju postižu učenici s CP koji su pohađali nastavu u redovnim inkluzivnim odjelima i učenici s CP koji su nastavu pohađali u posebnim odjelima redovnih osnovnih škola, zatim razlika u podršci koja im je omogućena, kao i međuodnos neophodne asistencije i/ili adaptacije i različitost utjecaja koji pružena fizička podrška ili kognitivno-biheviornalna podrška imaju na ostvarenu razinu participacije. Ukupno 148 ispitanika je podijeljeno u dvije grupe. Prvu grupu je činilo 100 učenika s CP koji su pohađali nastavu u redovnim inkluzivnim odjelima, dok je drugu grupu činilo 48 ispitanika s CP koji su nastavu pohađali u posebnim odjelima redovnih osnovnih škola. Grupe su bile statistički ujednačene prema dobi i spolu. Za utvrđivanje postignute razine participacije, sveukupne i one u okviru šest različitih školskih okruženja, korišten je prvi dio skale SFA, dok je za procjenu neophodne podrške koja je pružena u vidu asistencije (pomoć od strane odrasle osobe) ili adaptacije (kao modifikacije sredine, nastavnih sredstava i opreme i/ili u vidu modifikacije nastavnog plana i programa) korišten drugi dio iste skale. Statistički značajne razlike su nađene između ove dvije grupe ispitanika na svim skalama, odnosno između fizičkih i kognitivno-biheviornalnih asistencija i adaptacija. Utvrđeno je da je veća podrška, sa statistički značajnom razlikom, pružana grupi učenika s CP koji su uključeni u posebne odjele u odnosu na učenike s CP u redovnim odjelima. Također, sa statistički značajnom razlikom, češće je pružana fizička podrška i jednoj i drugoj grupi učenika s CP u odnosu na kognitivno-biheviornalnu podršku. Dalja analiza prikupljenih podataka sugerirala je da se osiguravanjem prvenstveno fizičke podrške, umjesto okolinskih modifikacija ili adaptacija, zapravo umanjuju mogućnosti za uspješnije socijalno uključivanje

učenika s CP koji pohađaju posebne odjele. Adaptacija sredstava i opreme, kao i pružanje veće podrške u području kognitivnih i bihevioralnih aktivnosti kao dopuna ili zamjena fizičke asistencije koju pružaju odrasle osobe, mogli bi stvoriti povoljnije mogućnosti za aktivnije i svestranije socijalno uključivanje učenika s CP, a samim tim i njihovo uspješnije akademsko i socijalno ostvarivanje. Značenje ovog istraživanja jest u potvrđivanju utjecaja koji asistencija i adaptacija, kao okolinski čimbenici, imaju na proces socijalnog uključivanja učenika s CP u redovno školsko okruženje, ali i u utvrđivanju njihovog međuodnosa.

Rezultati istraživanja osobnih i okolinskih čimbenika kao prediktora uključenosti u školsku sredinu koje su u SAD sprovedi Simeonsson, Carlson, Huntington, McMillen, i Brent (2001) ukazuju na dob, etničku pripadnost i stupanj oštećenja kao ključne prediktore školske participacije. U ovom deskriptivnom istraživanju korišten je posebno konstruiran upitnik *The National Survey of School Environments* (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001) kojim su prikupljeni podaci od 1180 nastavnika o školskoj sredini, dostupnim aktivnostima i socijalnoj uključenosti učenika s motoričkim poremećajima. Ispitanici su bili dobi od 5 do 18 godina. Manje uspješna socijalna participacija je zabilježena kod ispitanika mlađe dobi, južnoameričkog porijekla i težeg stupnja oštećenja, dok spol ispitanika nije imao veće statističko značenje. Također, participacija je bila najniža u manjim školama (s manje od 150 učenika), a najviše u školama s većim brojem učenika (s više od 750 učenika).

Eriksson (2005) je primijenila adaptiranu verziju upitnika koji su Simeonsson i sur. (2001) koristili u svom istraživanju. Upitnik je bio prilagođen školskom sustavu u Švedskoj i, za razliku od originalne verzije, koju su popunjavali nastavnici, odgovore su davali sami učenici s teškoćama. Istraživanje je bilo deskriptivno i usmjereno na utvrđivanje povezanosti okolinskih čimbenika i participacije u školskim aktivnostima, utjecaja općih i specifičnih okolinskih adaptacija na školsku participaciju, kao i način na koji angažiranje osobnog asistenta utječe na participaciju u različitim školskim aktivnostima. Nije bila potvrđena jaka statistički značajna povezanost između bilo kojeg okolinskog čimbenika ili pružene podrške i participacije u školi, osim između dostupnosti i školske participacije prema procjeni samih ispitanika. Utvrđeno je postojanje indikacija da pojedini specifični okolinski čimbenici imaju veći utjecaj nego opći okolinski čimbenici. Kao najjači okolinski čimbenik školske participacije izdvojila se učenikova samoprocjena dostupnosti, dok procjena dostupnosti od strane nastavnika i drugog stručnog osoblja nije imala statističko značenje. Podrška od strane osobnog asistenta djeluje također pozitivno na učenikovu samoprocjenu dostupnosti, ali istodobno djeluje i negativno na učenikovu samostalnost u školskim aktivnostima. Ovakvi rezultati govore u prilog potrebe da se buduća istraživanja usmjere na prikrivene potencijale ove populacije. Tip oštećenja, stupanj oštećenja, kao i broj prisutnih oštećenja (višestruka oštećenja) nisu imali zabilježen utjecaj na školsku participaciju, što je iste godine potvrđeno u istraživanju koje su, također u Švedskoj, napravili Almqvist i Granlund (2005). Utvrdili su da na visoku razinu socijalne

participacije učenika s teškoćama, uključujući i učenike s CP, utječe kombinacija različitih čimbenika, pri čemu je od većeg značenja broj onih čimbenika koji imaju pozitivan utjecaj na participaciju nego sastav pojedinih kombinacija. Kao ključne prediktore uspješnosti školske participacije ove djece izdvajaju pozitivne odnose s nastavnicima i vršnjacima i visok stupanj samostalnosti.

U Tablici 2. dat je prikaz izdvojenih istraživanja socijalne participacije djece s cerebralnom paralizom u školskom okruženju prema glavnim rezultatima, izvedenim zaključcima i osnovnim preporukama za budući naučni, profesionalni i stručni rad.

Tablica 1.

Tablica 2.

Rasprava

Pregled literature je pokazao da pri definiranju prediktora socijalne participacije djece s CP, nalazimo razlike od autora do autora, ali se svi slažu u jednom, a to je da postoji složen odnos između onesposobljenosti, participacije i školske sredine, a da je obujam participacije direktno zavisen od određenog broja međusobno povezanih čimbenika.

Participacija je u prezentiranim studijama uglavnom bila definirana sudjelovanjem u šest različitih okruženja u okviru školskog funkcioniranja i nađeno je da je za puno ili ograničeno sudjelovanje u svakom od tih okruženja odgovorno više varijabli i da nijedna varijabla nije sama po sebi jasan i dovoljan prediktor. Od studije do studije utvrđeno je da su najznačajniji prediktori participacije sljedeći: fizička funkcionalnost; stupanj samostalnosti; odnosi sa nastavnicima i vršnjacima; fine i grube motoričke sposobnosti; sposobnost oblačenja; tip podrške; prisustvo nekog od pratećih neuroloških oštećenja; učenikova samoprocjena dostupnosti; dob; etnička pripadnost; veličina škole, asistencija i adaptacija, pri čemu se neki od njih mogu svrstati u skupinu osobnih a drugi u skupinu okolinskih čimbenika.

Zanimljivo je da u pitanju stupnja motoričkog oštećenja, kao prediktora socijalne participacije djece s CP, nailazimo na koliziju između rezultata iz SAD, Izraela i Švedske. U istraživanjima iz SAD-a i Izraela više razine participacije su u jakoj vezi s nižim stupnjem oštećenja, dok su švedske studije rezultirale saznanjem da tip, stupanj i broj oštećenja nisu od značenja za obujam participacije u školi. Vjerujemo da je ta razlika rezultat toga što je u studijama u SAD i Izraelu definiranje prediktora participacije bilo objektivnije nego u švedskim studijama, gde su prediktori definirani na temelju učenikove samoprocjene. Zbog toga, skloniji smo uvjerenju da viši stupanj motoričkog oštećenja i veći broj oštećenja predstavljaju čimbenike rizika za participaciju u punom obujmu. S druge strane, tip oštećenja može i ne mora biti čimbenik rizika, s obzirom na to da je od samog tipa oštećenja, po socijalnu kompetenciju bitnija razina funkcionalnih sposobnosti.

Nužno je naglasiti da spomenuta skupina prediktora ne predstavlja ništa drugo do sintetizirane podatke o prediktorima, koji se ne pojavljuju istom frekventnošću u svim prezentiranim studijama. Čimbenik koji dominira u određivanju participacije djece s CP u školskom okruženju je fizička funkcionalnost djece. S obzirom na to da je njegovo značenje prepoznato u svim studijama, jedini je za koji bismo se usudili generalizirati i reći da svakako određuje obujam participacije.

Što se tipa podrške tiče, pokazalo se da podrška može biti u isto vrijeme i protektivni i čimbenik rizika. Tako je fizička podrška protektivni čimbenik u jednom, ali istodobno i čimbenik rizika za participaciju u drugim oblastima funkcioniranja u školskom okruženju (poput samostalnosti) i predstavlja prediktor ograničene participacije. S druge strane, pokazalo se da je kognitivno-biheviorna podrška isključivo protektivni čimbenik i prediktor participacije u punom obujmu.

Bez obzira na kompleksnost problema i otežano identificiranje pojedinačnih prediktora, prepoznato je značenje kako osobnih tako i okolinskih čimbenika i njihove interakcije, kao i utjecaj osobnih obilježja djece s CP u vidu njihovih fizičkih, odnosno motoričkih sposobnosti i kognitivno-biheviornih performansi.

Zaključci

U ovom radu prikazano je osam studija dizajniranih s ciljem da se identificiraju prediktori socijalne participacije djece s CP. Dvije studije su imale u svom fokusu osobne čimbenike od utjecaja na socijalnu participaciju djece s CP, jedna okolinske čimbenike dok su preostalih pet fokusirane za definiranje i osobnih i okolinskih čimbenika. Svega tri studije su u uzorku imale isključivo djecu s CP, dok su u preostalih pet studija djeca s CP bila poduzorak u uzorku djece s motoričkim poremećajima i ometenošću uopće. Uslijed toga, osnovna ograničenja ovog rada su u direktnoj vezi s ograničenjima prezentiranih studija, prvenstveno zbog malog broja istraživanja na ovu temu i zbog činjenice da se iz pet studija koje za uzorak nisu imala isključivo djecu s CP ne mogu izolirati podatci koji se odnose samo na ovu populaciju, već se moraju promatrati u sklopu cjelovitog uzorka. S druge strane, činjenica da su se za definiranje prediktora u prikazanim studijama koristila samo dva osnovna mjerna instrumenta, skala *The School Function Assessment (SFA)* – Dio 1 (Participacija), Dio 2 (Pružena podrška) i Dio 3 (Izvođenje aktivnosti) u pet studija i *The National Survey of School Environments* (originalna i adaptirana verzija) u tri studije, omogućena je kvalitetnija sinteza podataka iz različitih studija.

Sve navedeno u prikazanim studijama, bez obzira na činjenicu da se istraživanja odnose na školske sustave i edukativne linije specifične za države iz kojih potječu, upućuje na zaključak da je participacija u školskom životu važan čimbenik biopsihosocijalnog razvoja djeteta kao zdrave, nezavisne jedinke i aktivnog člana društva. Uključivanje u svakodnevne, školske i izvanškolske, aktivnosti osnova je razvijanja socijalnih vještina i mreže socijalne podrške svakog djeteta, dok angažiranje u aktivnostima umanjene kvalitete i niže frekventnosti može negativno utjecati na uspostavljanje socijalnih odnosa, prilagođavanje i kvalitetu života.

Ipak, i pored određene skupine sintetiziranih podataka, malo je onih zaključaka koji se mogu generalizirati, pa se tako funkcionalna aktivnost i participacija djece s CP mogu adekvatno objasniti jedino kombiniranim utjecajem fizičkih i kognitivno-bihevioralnih varijabli, kao i interakcijom osobnih i okolinskih čimbenika. Činjenica je da su fizičke varijable od značenja samo za djelimičnu, ograničenu participaciju, a da su kognitivno-bihevioralne varijable neophodne za ostvarivanje participacije u punom obujmu. Što se utjecaja osobnih i okolinskih čimbenika tiče, mnogo se više naglašava značenje okolinskih čimbenika kao facilitatora participacije, u odnosu na osobne. Međutim, dojmama smo da je zanemareno značenje osobnih čimbenika za participaciju djece s CP, jer bi kreiranje stručnih programa usmjerenih na okolinske čimbenike moglo rezultirati nedovoljnim angažiranjem u jačanju osobnih performansi djeteta. Dakle, jačanje osobnih kapaciteta djece i istodobno djelovanje na okolinske čimbenike predstavljalo bi temelj sveobuhvatne akcije usmjerene k potpunoj socijalnoj uključenosti ove djece.

Ključni koraci u stručnom interveniranju podrazumijevali bi razvijanje strategija kojima će se omogućiti djeci s CP da u punoj mjeri iskoriste mogućnosti koje svakodnevne školske aktivnosti pružaju u pogledu aktivnog socijalnog uključivanja, kao i edukaciju školskog osoblja za kreiranje situacija u kojima će djeca biti aktivni sudionici, uz nezaobilazno poticanje recipročnih interakcija između djece s CP i njihovih vršnjaka iz redovne populacije, s ciljem punog ostvarivanja socijalne participacije. Također, slobodni smo preporučiti i da sve školske aktivnosti budu strukturirane i planirane tako da svojom realizacijom isključuju bilo kakav vid diskriminacije, s obzirom na to da se socijalna integracija najpotpunije postiže upravo sudjelovanjem u zajedničkim aktivnostima, osiguranjem afirmativnih iskustava u interakcijama između djece iz tipične populacije i djece s CP i unapređenje socijalnih vještina djece s CP.

Konačno, na temelju saznanja dobivenih ovim pregledom i analizom literature, može se zaključiti da je ovo znanstveno i stručno područje još uvijek nedovoljno osvijetljeno. Potrebna su dalja istraživanja koja bi pomogla adekvatnijem identificiranju prediktora, protektivnih čimbenika i čimbenika rizika za participaciju djece s CP i omogućila potpunije definiranje modela varijabli koji bi se mogli generalizirati. To bi omogućilo kreiranje školskog okruženja kao konteksta u kome će i djeca s CP moći, na isti način i u istom obujmu kao i njihovi vršnjaci, usvajati akademske vještine i društvene norme, formirati svoju ličnost i stjecati socijalne kompetencije, što će se sve moći transferirati iz inkluzivnog školskog okruženja u sve oblike društvenog života, čime se ostvaruje krajnji cilj i edukacije i rehabilitacije djece s CP, a to je najostvarljivija moguća participacija i socijalna integracija.