

Experiences of Students with Cerebral Palsy in Regular Primary Schools

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KLJUČNE BESEDE: cerebralna paraliza, večinska osnovna šola, vključenost, učitelji, starši, učenci

POVZETEK – V prispevku se osredotočamo na izkušnje učencev s cerebralno paralizo v prvih petih razredih večinske osnovne šole, kot so jih zaznali učitelji ($n = 27$) in starši ($n = 23$) ter so jih zase opisali trije učenci s cerebralno paralizo. Starši in učitelji so izpolnili spletni vprašalnik, z učenci s cerebralno paralizo pa smo izvedli polstrukturirani intervjuju. Večina staršev in učiteljev ter vsi učenci so vključitev učencev v razred ocenili kot (zelo) dobro. Starši in učitelji so izpostavili pomembne predhodne (npr. informiranje drugih otrok in staršev o cerebralni paralizi) in aktualne dejavnike (npr. interakcije s sošolci), ki so prispevali k vključitvi otroka v razred, vsi učenci pa so kot pomembne za vključitev izpostavili medosebne odnose s sošolci. Največ težav pri šolskem delu so učitelji in učenci s cerebralno paralizo prepoznali na psiho-fizičnem, socialno-emocionalnem in verbalnem področju. Večina staršev, učiteljev in učencev je poročala o dobrem sodelovanju z drugimi strokovnjaki na šoli.

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ABSTRACT – The present study focuses on the experiences of students with cerebral palsy in the first five grades of regular primary schools, as perceived by teachers ($n = 27$) and parents ($n = 23$), and as described by three students themselves. The parents and teachers completed an online questionnaire, and semi-structured interviews were conducted with the students with cerebral palsy. Most of the parents and teachers, as well as all of the students, rated the student's involvement in the classroom as (very) good. The parents and teachers highlighted important past factors (e.g., informing other students and parents about cerebral palsy) and current factors (e.g., interactions with classmates) that contributed to the student's inclusion in the classroom, while all of the students highlighted their relationships with classmates. Most problems with schoolwork were identified by the teachers and the students with cerebral palsy in the psychophysical, socioemotional and verbal domains. Most of the parents, teachers and students reported good cooperation with other professionals in the school.

1 Introduction

Cerebral palsy is a movement and postural or coordination disorder that occurs as a result of non-progressive damage to the brain of a developing foetus or an infant (Sonček.org, n. d.). About two-thirds of people with cerebral palsy have speech, behavioural, visual and hearing impairments, while half of them have cognitive impairments ($IQ < 70$). Learning and emotional difficulties are also common. In one-third of these children, cerebral palsy is associated with epilepsy (Brossard-Racine, 2012; Horber et al., 2000; Radšel and Jekovec Vrhovšek, 2014; Terzić et al., 2012). In some individuals, cerebral palsy may manifest itself in a very mild form, while in others it appears in a more severe form (Schenker, Coster and Parush, 2006). In Slovenia (Vrlič Danko, 2005) and worldwide (Sellier et al., 2016), the incidence of cerebral palsy is reported to be approximately 3 per 1000 live births.

Children with special needs may be referred to an appropriate education programme (ZUOPP, 2011). This is also the case for children with cerebral palsy. Those children (with cerebral palsy) who are able to successfully participate in regular schools may be enrolled in a regular primary education programme with adapted implementation and additional professional support (Mori, 2002). Children with cerebral palsy who are enrolled in such a programme may receive additional professional help designed to overcome their deficits, barriers or disruptions (ZUOPP, 2000). Children with severe cerebral palsy may be assigned a temporary or permanent companion during the implementation of the compulsory and extended primary education programme. This companion provides support in work organisation, writing and moving around the classroom, as well as in establishing contact with other professionals who monitor the child's development (Zobec, 2012).

When working with special needs students, teachers should be adequately trained to recognise their behavioural characteristics and learning specifics, and should cooperate with parents and other professionals (Mijanović, 2019, p. 141). "When teachers and parents cooperate, children aspire to achieve more [...]" (Berčnik and Devjak, 2018, p. 65). The results of a survey on the quality of cooperation between teachers and parents in Slovenian primary schools (Kalin et al., 2009) show that both teachers and parents are aware of the importance of mutual cooperation. Intihar and Kepec (2002) summarised the findings of several studies (e.g., Becher, 1986; Conoley, 1987; Epstein and Henderson, 1992) that emphasise the importance of cooperation between teachers and parents for improved academic achievement of students, development of learning and working habits, better participation in the classroom, development of self-esteem and social skills, building a quality relationship with the school, etc. It is important that teachers and parents express mutual respect for each other and demonstrate a genuine interest in the student, which is the basis for any quality cooperation with others (Štemberger, 2013, p. 6).

The present study was one of the first in Slovenia and worldwide to focus on the experience of students with cerebral palsy in regular primary schools from the perspective of different assessors (teachers, parents and the students themselves). We were interested in detailed information on how teachers, parents and students perceived the student's or their own involvement in the classroom, what problems teachers and parents perceived regarding student's schoolwork and how the students themselves described their problems, and how teachers, parents and students interacted with other professionals involved in teaching (e.g., with a special and rehabilitation pedagogue).

2 Method

2.1 Sample

The study included 27 teachers (93 % female) who taught students with cerebral palsy in regular primary schools, 23 parents of students with cerebral palsy, and three students (adolescents with cerebral palsy). The latter were two boys, aged 11 and 12, who attended fifth and sixth grade of regular primary school, respectively, and a 16-year-old girl who attended the first grade of regular secondary school. The adoles-

cents reported their school experiences retrospectively, that is, for the period during which they attended the first five grades of regular primary school. The majority of the teachers (20 or 74.1 %) had taught students with cerebral palsy for one year, while four teachers (17%) had taught such students for two years, two teachers (7%) for three years or more, and one teacher (4%) for less than one year.

2.2 Procedure

We obtained information about students with cerebral palsy in the first five grades of regular primary schools from the University Rehabilitation Institute – Soča in Slovenia. We then contacted the relevant school principals, who gave teachers and parents access to online questionnaires to complete within a month. After obtaining the consent of the parents and adolescents, we conducted interviews with the three adolescents with cerebral palsy, which we recorded and then transcribed verbatim. Anonymity of the data obtained from the teachers, parents and adolescents was ensured.

2.3 Instruments

The questionnaires for the teachers and parents included data on gender and questions on the characteristics of the student's experiences in class, the domains in which the student had difficulties in school, and the characteristics of cooperation between the student, parents and other school professionals. The semi-structured interview for the adolescents involved questions about their inclusion in class, difficulties with school work, and cooperation with teachers and other school professionals. The content of the questionnaire and interview are described in more detail in the results.

2.4 Data analysis

Data from the questionnaires were processed using SPSS Statistics 22.0. Basic descriptive statistics were calculated for ordinal and interval data, and teacher and parent responses on an interval scale were compared using the Mann-Whitney test because the data were not normally distributed (Shapiro-Wilk test, $p < 0.00$). The responses in the interviews with adolescents were analysed using the content analysis method (Vogrinc, 2008).

3 Results and discussion

3.1 Inclusion of students with cerebral palsy in the classroom

Regarding the inclusion of students with cerebral palsy, we asked the teachers/parents: "In your opinion, how well was the student/your child included in the class?". The answers were given on a 4-point scale (1 – very well, 2 – well, 3 – poorly, 4 – very

poorly). The majority of the parents (70%) judged that their child had been included in the class “very well”, while this rating was given by far fewer teachers (26%). Some 26% of the parents and 56% of the teachers judged that the students/their child had been included “well”. Only one parent chose the rating “poorly”. Of the teachers, three judged that the student had been included in the classroom “poorly” and two gave the rating “very poorly”. There were also statistically significant differences between the groups of teachers and parents in assessments of the success of the student’s/their child’s inclusion in the classroom (Mann-Whitney $U = 166.500$, $p = 0.00$): the parents ($Me = 2.00$) rated their child’s inclusion in the classroom statistically significantly better than the teachers rated the inclusion of their students ($Me = 1.00$).

We asked the adolescents: “How well do you think you were accepted in the class?”. All three adolescents responded that they had been accepted well in their class.

The teachers, parents and adolescents described in their own words the experience of the student’s/their child’s/their own inclusion in the class. The teachers’ and parents’ results are presented in Table 1, and the adolescents’ responses are presented below.

Table 1

Factors highlighted by the teachers and parents as important for the inclusion of students with cerebral palsy in the classroom

<i>Factors of inclusion</i>	<i>Factor description</i>	<i>Teacher</i>		<i>Parent</i>	
		<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>
Preliminary factors influencing the student’s easier inclusion in the classroom	Prior acquaintance with classmates	3	11.1	4	18.2
	Personality of the student	6	22.2	2	9.1
	Age of classmates	1	3.7	1	4.5
	Informedness of classmates about cerebral palsy	1	3.7	5	22.7
	Informedness of parents about cerebral palsy	/	/	2	9.1
Current factors that reflect the student’s inclusion in the classroom	Socioemotional domain				
	Acceptance by classmates	13	48.1	9	40.9
	Help from classmates	8	29.6	4	18.2
	Interaction with peers	7	25.9	3	13.6
	Equal relationship	3	11.1	/	/
	Close friendship	2	7.4	/	/
	Educational domain				
	Involvement in school activities	8	29.6	/	/
	Student’s attitude towards school	4	14.8	4	18.2
	Student’s success/failure at school	1	3.7	2	9.1
	Other factors	1	3.7	2	9.0

The results show that the teachers and parents emphasised both preliminary factors that influenced the student’s ease of inclusion in the classroom and more current fac-

tors of inclusion. Among the preliminary factors of the student's/their child's inclusion in the classroom, the teachers (11 responses) and parents (14 responses) pointed to prior acquaintance with classmates (e.g., Teacher 20: "*They were together already in kindergarten, so they were connected.*"), the student's/their child's personality (e.g., Teacher 24: "*The student was pretty introverted, had trouble socialising.*"), and the information that classmates and their parents' had about cerebral palsy (e.g., Parent 5: "*In class, the classmates were told why he cannot do certain things as they do.*").

Among the important current factors in the inclusion of a student with cerebral palsy in the classroom, the teachers and parents highlighted two domains: the socioemotional domain (22 responses from the teachers and 16 responses from the parents) and the educational domain (15 responses from the teachers and 8 responses from the parents). Within the socioemotional domain, the teachers highlighted the acceptance of the student by classmates (e.g., Parent 3: "*She was very well accepted in class.*"); interaction between the student and classmates (e.g., Parent 8: "*In the lower grades they played with her.*"); help provided to the student by classmates (e.g., Teacher 18: "*They helped him when he needed help.*"); the equal attitude of classmates towards the student with cerebral palsy (e.g., Teacher 2: "*The classmates accepted her as an equal.*"); a close friendship between the student and a classmate (e.g., Teacher 11: "*He had a best friend.*"). Among the educational factors that contributed to the successful inclusion of a student with cerebral palsy in the classroom, the teachers and parents highlighted the student's/their child's participation in class/school activities (e.g., Teacher 3: "*She was involved in all activities.*"), attitude towards school (e.g., Teacher 5: "*He was actively involved in class.*"), and success/failure at school (e.g., Teacher 26: "*The student did not catch up with his classmates in school.*").

The adolescents were asked two questions about their perceptions of their inclusion in the classroom: "How included do you feel?" and "How would you otherwise rate your contacts/interactions with classmates in your first five years of primary school?" All three adolescents described their inclusion as good. In assessing inclusion, they all emphasised acceptance by classmates (e.g., Adolescent 1: "*I also got along well with classmates in the first grade.*").

The results obtained from the parents, teachers and adolescents show that the inclusion of students with cerebral palsy proceeds well in most primary schools. However, special attention should be paid to factors that are important before the student enters the classroom. Among all of the factors, the adolescents emphasised the importance of being accepted by classmates. Various authors (e.g., Košir, 2012, p. 105; Peček and Lesar, 2006) have found that the condition for students' acceptance in the classroom is a good class atmosphere, where a sense of belonging, solidarity and care for others prevails. Consequently, it is particularly important to pay attention to this when working with students (with cerebral palsy).

3.2 Problems of students with cerebral palsy regarding school work

In order to identify the problems of students with cerebral palsy at school, we asked teachers: "In which three domains does a student with cerebral palsy have the most problems?". Parents answered the question: "In which school subject do you notice that

your child has the most problems?”. The adolescents replied to the following questions: “What causes you the most problems at school?” and “In which subjects do you have problems?”. The teachers’ and parents’ responses are shown in Table 2.

Table 2

Domains and school subjects in which students with cerebral palsy had the greatest problems

Problematic domains	Description of the problem	Teachers on the domains in which students had the greatest problems		Parents on the school subjects in which students had the greatest problems	
		<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>
Psychophysical characteristics	Tiredness	11	40.7	1	4.3
	Pace of schoolwork	2	7.4	/	/
Socioemotional domain	Social relations	10	37.0	/	/
	Dependence	2	7.4	/	/
	Fear of failure	2	7.4	/	/
Verbal skills	Speech	5	18.5	/	/
	Oral presentations	3	11.1	/	/
Motor domain	Movement	9	33.3	/	/
	Sports	5	18.5	/	/
	Problems with hands	4	14.8	/	/
	Problems with writing	8	29.6	2	8.7
Cognitive skills	Abstract thinking	2	7.4	4	17.4
Mathematics	Concrete knowledge	3	11.1	15	65.2
	Spatial representations	7	25.9	5	21.7
	Arithmetic	4	14.8	2	8.7
	Geometry	3	11.1	4	17.4
Languages	Foreign languages	2	7.4	4	17.4
	Difference between phonetics and spelling	/	/	2	8.7
	Slovenian language	/	/	4	17.4
	Reading	/	/	1	4.3
Other subjects	Visual art	2	7.4	2	8.7
	Technical education	/	/	2	8.7
	Physics	/	/	1	4.3
Absence of problems	/	/	/	2	8.7
Other	Other	4	14.8	4	17.4

The teachers named the domains in which the student with cerebral palsy had the most problems as follows: psychophysical characteristics (11 responses), the soci-

oemotional domain (11 responses), verbal skills (8 responses), the motor domain (9 responses), cognitive skills (2 responses) and specific problems manifested mainly in mathematics, foreign languages and other subjects (21 responses).

In terms of psychophysical characteristics, the teachers mainly emphasised the student's fatigue (e.g., Teacher 23: "*Fatigue. Although he never complained, there were signs of fatigue in the second half of the lesson.*"), which is consistent with the fact that students with cerebral palsy often also have a weak physical constitution and are less physically active, so they are often physically tired (Sonček.org, n. d.).

In the socioemotional domain, teachers emphasised the difficulties that the student with cerebral palsy had in establishing social contacts with peers (e.g., Teacher 16: "*The student had difficulties in socialising with peers.*").

In the domain of verbal skills, speech and oral presentation were mentioned by the teachers as problematic (e.g., Teacher 23: "*At the beginning, he had problems with oral presentation, but with encouragement his performance improved.*"). Speech problems in people with cerebral palsy occur mainly due to poor control of the muscles in the oral cavity, which makes it more difficult for some of them to express themselves (Sonček.org, n. d.).

In the domain of motor skills, the teachers emphasised the student's problems with movement (e.g., Teacher 17: "*Problems with movement.*"), related difficulties in sports activities (e.g., Teacher 1: "*Sports activities.*") and problems with fine motor skills (e.g., Teacher 4: "*Fine motor skills: the student had problems with all activities related to writing, drawing, dressing and other skills.*"). The basic feature of cerebral palsy is the inability to control motor activities (Sonček.org, n. d.). This was also recognised by the teachers in our research on students with cerebral palsy.

Among problems with cognitive skills, the teachers highlighted the development of abstract thinking in students with cerebral palsy (e.g., Teacher 25: "*She has difficulty with more abstract content.*"). Consistent with the teachers' reports, Haskell and Barret (1993) also found that many people with cerebral palsy have problems with more abstract thinking.

Regarding specific problems, both the teachers (3 responses) and the parents (15 responses) mentioned that the most common problems were in mathematics (e.g., Parent 15: "*It is common knowledge that it is very difficult to understand mathematics when suffering from cerebral palsy.*"). When describing specific problems in mathematics, problems with spatial representation and orientation were mentioned more frequently, while some respondents highlighted problems in geometry and arithmetic. Similar observations have been made by Vrlič Danko (2005), who notes that students with cerebral palsy have more difficulties in learning mathematics.

The parents (11 responses) reported problems in language subjects to a greater extent than the teachers (2 responses). In foreign languages, especially English, the parents indicated difficulties their child had in writing words because phonetic pronunciation differs from what is written (e.g., Parent 22: "*Maybe in writing English words because he writes by ear or by pronunciation.*"). In Slovenian language, on the other hand, they pointed to problems with fine motor skills due to which their child had problems writing (e.g., Parent 6: "*In Slovenian, because of writing problems.*"). Reading and writing

problems, as well as problems with fine motor skills, were also found in Vrlič Danko's (2005) study of students with cerebral palsy.

Both the teachers and the parents also mentioned problems in visual arts (2 teacher responses and 2 parent responses), mainly related to the use of assistive devices (e.g., Teacher 19: "*Problems with visual arts, use of assistive devices, except for drawing.*"). Vrlič Danko (2005, p. 90) similarly found that students with cerebral palsy have difficulties with drawing.

Two parents answered that they did not notice any problems with their child (e.g., Parent 3: "*So far, because our child is in the first grade and there are no noticeable differences between students.*"). Parent assessment of this kind can be related to research findings (Vrlič Danko, 2005) indicating that some students with cerebral palsy do not show major problems in perceptual-motor and cognitive functioning and do not have learning difficulties.

The adolescents who participated in the study reported that they had the most problems with fine motor skills (e.g., cutting, drawing, writing, using geometric tools) in schoolwork. In relation to specific subjects, all three adolescents highlighted mathematics problems due to difficulty using geometric tools (e.g., Adolescent 2: "*Using a compass in maths.*") and arithmetic problems (e.g., Adolescent 3: "*In some maths problems, seemingly logical processes and calculations; well, I am not a 'logician'.*"). Two of the adolescents also mentioned problems in fine motor skills (e.g., Adolescent 2: "*In fine motor skills, precision in drawing, cutting.*").

The overall results regarding the domains and school subjects in which students with cerebral palsy had the most problems show that motor problems are most directly related to cerebral palsy, with some additional problems compounding these primary difficulties (e.g., in the socioemotional domain, psychophysical characteristics, verbal and cognitive skills). Other studies (e.g., Horber et al., 2000) also report problems in students with cerebral palsy that affect not only the motor domain but other domains as well. Therefore, when planning a support programme for a student with cerebral palsy, it is necessary to take into account his/her specific problems and abilities, and to construct an individualised work plan.

3.3 Cooperation with other professionals in working with a student with cerebral palsy

The teachers, parents and students involved in the survey also rated their cooperation with other professionals. The parents and teachers answered the question: "How would you rate your cooperation with...?". Responses were given on a 4-point scale (1 – very good, 2 – good, 3 – poor, 4 – very poor).

The results indicated that the parents rated cooperation with the special and rehabilitation pedagogue (Me = 1.00) and the teacher (Me = 1.00) as "very good" and cooperation with others (school management, other teachers, and "other") as "good" (Me = 2.00). The teachers rated cooperation with parents (Me = 1.00) and the special and rehabilitation pedagogue (Me = 1.00) as "very good" and cooperation with others (students, other teachers, school management) as "good" (Me = 2.00). Thus, the given

assessments indicate (very) good cooperation between teachers, parents, special and rehabilitation pedagogues and other parties involved in the process. The assessments of the teachers and parents regarding the cooperation with school management, special and rehabilitation pedagogues, supervisors and “other parties involved” did not differ significantly (Mann-Whitney U test, $p > 0.05$).

Regarding cooperation with others, we asked the adolescents the following questions: “How would you describe working with teachers in the first five grades of primary school?” and “In the first five grades, did you cooperate with anyone who helped you learn, such as a special and rehabilitation pedagogue? How would you rate that cooperation?”. All three adolescents rated cooperation with teachers as relatively good. Two responded that they got along with teachers well (e.g., Adolescent 2: “*I got along with teachers well.*”), and one adolescent indicated that the quality of the relationship depended on the particular teacher (Adolescent 3: “*I got along very well with some, but a little less with others.*”). The adolescents mentioned the provision of help (Adolescent 2: “*When I needed something, they came to my rescue.*”) and equal treatment (Adolescent 3: “*I liked that they did not make a distinction between me and my classmates.*”). All three adolescents described a positive relationship with the special and rehabilitation pedagogue who helped them with school work (e.g., Adolescent 3: “*Towards the end, we also worked on materials that my classmates were working on in a regular lesson.*”).

The results show that the parents, teachers and adolescents all rated cooperation with others as relatively good. This is encouraging, as good cooperation between all those who work with students in the school context is a prerequisite for quality work with them (e.g., Marentič Požarnik, 2003).

4 Conclusions

The responses from the teachers, parents and adolescents involved in the survey indicate that the inclusion of students with cerebral palsy is proceeding well in the majority of regular primary schools. The parents and teachers pointed to some factors contributing to good school inclusion that take place before the student enters the class (e.g., informing other students in the class and their parents about the characteristics of cerebral palsy) and some factors that are expressed during the student’s ongoing participation in the class (e.g., acceptance by classmates). Relationships with classmates are also important for all adolescents. The teachers, parents and adolescents emphasised major problems encountered by the student/child (or themselves) in mathematics, languages and art, as well as problems that are either directly (e.g., motor problems) or indirectly (e.g., socioemotional problems) related to cerebral palsy. The teachers, parents and adolescents reported that they were mostly satisfied with the cooperation with other professionals in the school. The teachers’ and parents’ assessments did not differ significantly in terms of satisfaction with the cooperation with other professionals.

The results obtained, which involve various informants, provide new insights into the school experiences of students with cerebral palsy in regular primary schools. These findings can help to better plan and implement work with students with cerebral palsy,

taking into account not only the motor dimension, but also the socioemotional aspect of education. When working with students with cerebral palsy, their individual characteristics, problems and abilities should be taken into account, as people with cerebral palsy differ greatly from one another.

The study could be improved by including a larger number of students, who could report on their current school experience rather than past experiences (in the first five grades of primary school). Interviews could also be conducted with some teachers and parents to obtain more in-depth information on the experience of students with cerebral palsy in school.

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Izkušnje učencev s cerebralno paralizo v večinskih osnovnih šolah

Cerebralna paraliza je motnja gibanja in drže, ki nastane kot posledica nenapredujoče okvare možganov razvijajočega se ploda ali dojenčka (Sonček.org, b. d.). Za približno dve tretjini oseb s cerebralno paralizo so značilne govorno-jezikovne motnje, vedenjske motnje ter motnje vida in sluha, za približno polovico znižane kognitivne sposobnosti ($IQ > 70$), pogoste pa so tudi učne težave in težave na področju čustvovanja, tretjina otrok s cerebralno paralizo pa ima pridruženo epilepsijo (Brossard-Racine, 2012; Horber idr., 2000; Radšel in Jekovec Vrhovšek, 2014; Terzić idr., 2012). Pri nekaterih osebah se cerebralna paraliza lahko izrazi v zelo blagi obliki, pri drugih pa v težji (Schenker, Coster in Parush, 2006). V Sloveniji (Vrlič Danko, 2005) in v svetu (Sellier idr., 2016) je pogostost cerebralne paralize prepoznana pri približno 3 otrocih na 1000 živorojenih otrok.

V Zakonu o usmerjanju otrok s posebnimi potrebami (ZUOPP, 2011) je zapisano, da otroke s posebnimi potrebami lahko usmerimo v enega izmed ustreznih vzgojno-izobraževalnih programov, kar velja tudi za otroke s cerebralno paralizo. V program večinskega osnovnošolskega izobraževanja s prilagojenim izvajanjem in dodatno strokovno pomočjo so lahko vključeni otroci (tudi s cerebralno paralizo), ki so se zmožni uspešno vključiti v večinsko šolanje (Mori, 2002). Ko se otroci s cerebralno paralizo vključijo v večinsko šolanje, imajo možnost dodatne strokovne pomoči, ki je namenjena premagovanju njihovih primanjkljajev, ovir oz. motenj (ZUOPP, 2000). Težje in težko gibalno oviranim otrokom, med katere uvrščamo tudi del otrok s cerebralno paralizo, se lahko v času izvajanja obveznega in razširjenega programa osnovne šole dodeli stalnega ali začasnega spremljevalca (ZUOPP-1, 2011). Ta otroku pomaga pri organizaciji dela, pisanju in premikanju po prostoru, povezuje pa se tudi s pedagoškimi in svetovalnimi delavci ter po potrebi tudi z drugimi strokovnjaki, ki spremljajo otrokov razvoj (Zobec, 2012).

Učitelji naj bi bili za delo z učenci s posebnimi potrebami ustrezno usposobljeni, da prepoznajo vedenjske značilnosti in učne posebnosti, pri delu z učenci naj bi izbrali učinkovite učne metode, dobro naj bi sodelovali s starši, z drugimi učitelji, s šolskimi svetovalnimi delavci ter z drugimi specializiranimi strokovnjaki in institucijami (Berčnik in Devjak, 2018; Mijanović, 2019; Štemberger, 2013; Vovk Ornik, 2016). Intihar in

Kepec (2002) navajata ugotovitve različnih raziskav (npr. Conoley, 1987; Epstein in Henderson, 1992), ki kažejo na pomen dobrega sodelovanja med učitelji in starši, da je otrok učno uspešen, razvija učne in delovne navade, sodeluje pri pouku, razvija samospoštovanje in socialne spretnosti, vzpostavlja kakovosten odnos do šole idr.

Raziskava, opisana v tem prispevku, je ena prvih v svetu in pri nas, ki vključuje izkušnje s poučevanjem otrok s cerebralno paralizo, kot so jih zaznali učitelji in starši ter jih zase opisali učenci s cerebralno paralizo (triangulacija virov podatkov).

V raziskavi nas je zanimalo:

- kako so učitelji/starši/učenci sami zaznali učenčevo/otrokovo/svoje vključevanje v razred,
- katere težave so učitelji oz. starši zaznali pri šolskem delu učenca oz. njihovega otroka in kako so svoje težave opisali učenci sami in
- kako so učitelji/starši/učenci sodelovali z drugimi strokovnjaki, ki so bili vključeni v poučevanje (npr. s specialnim in rehabilitacijskim pedagogom).

V raziskavi je sodelovalo 27 učiteljev (93 % ženskega spola), ki so poučevali otroke s cerebralno paralizo v večinski osnovni šoli, 23 staršev otrok s cerebralno paralizo in trije mladostniki s cerebralno paralizo (obiskovali so 5. in 6. razred osnovne šole ter 1. letnik srednje šole), ki so svoje izkušnje s šolanjem v prvih petih razredih osnovne šole opisovali "za nazaj". Otroke s cerebralno paralizo je večina učiteljev (20 oz. 74,1 %) poučevala eno leto, 4 učitelji (17 %) dve leti, 2 učitelja (7 %) tri leta, en učitelj (4 %) pa manj kot leto dni.

Pred izvedbo raziskave smo na Univerzitetnem rehabilitacijskem inštitutu – Soča pridobili informacije o učencih s cerebralno paralizo, ki so bili vključeni v prvih pet razredov večinske osnovne šole. Nato smo prošnjo za sodelovanje v raziskavi naslovili na ravnatelje osnovnih šol, ki so jih obiskovali otroci s cerebralno paralizo. Po pridobljenem soglasju smo dostop do spletnih vprašalnikov posredovali učiteljem otrok s cerebralno paralizo in staršem, katerih otrok se je šolal v enem od prvih petih razredov večinske osnovne šole. Trije starši otrok s cerebralno paralizo so soglašali, da z njihovimi otroki (sicer že mladostniki, ki so se šolali v večinski osnovni šoli) izvedemo intervjuje, s tem pa so soglašali tudi vključeni mladostniki sami. Vsak intervju z mladostnikom smo posneli in ga dobesedno prepisali. Učiteljem, staršem in mladostnikom smo zagotovili anonimnost pridobljenih podatkov.

V raziskavi smo uporabili dva vprašalnika – za učitelje in starše, in polstrukturirani intervju za vključene tri mladostnike. Vprašalnika za učitelje oz. starše sta v prvem delu vključevala podatke o spolu, sledila pa so vprašanja o otrokovi vključitvi v razred, področjih, na katerih je imel v šoli težave, in njihovem sodelovanju z drugimi strokovnimi delavci šole (npr. s specialnim in rehabilitacijskim pedagogom). Nekatera vprašanja so bila odprtega tipa, vprašanja o kakovosti vključevanja otrok v šolo in o sodelovanju z drugimi strokovnjaki pa so vključevala 4-stopenjsko lestvico (1 – zelo dobro, 2 – dobro, 3 – slabo in 4 – zelo slabo). Za mladostnike smo oblikovali polstrukturirani intervju z vprašanji o tem, kako so se vključili v razred, na katerih področjih so se soočali s težavami pri šolskem delu ter kakšno je bilo njihovo sodelovanje z učitelji in drugimi strokovnimi delavci šole.

Rezultati so pokazali, da so starši, učitelji oz. mladostniki otrokovo oz. svojo vključitev v razred ocenili kot (zelo) dobro. Med učitelji in starši smo ugotovili statistično pomembne razlike v ocenah vključitve otroka s cerebralno paralizo v razred (Mann-Whitney preizkus: $U = 166,500$, $p = 0,00$). Starši ($Me = 2,00$) so otrokovo vključitev v razred ocenili bistveno bolje kot učitelji ($Me = 1,00$). Starši in učitelji so izpostavili podobne dejavnike/pogoje, ki so bili pomembni za vključenost otroka s cerebralno paralizo v razred: nekaterim dejavnikom/pogojem za uspešno vključevanje otroka v razred je bilo potrebno zadostiti že pred njegovim prihodom v razred (npr. informiranje sošolcev in njihovih staršev o značilnostih cerebralne paralize), drugim pa v času otrokove vključenosti v razred, tj. na socialno-emocionalnem (npr. interakcija otroka z vrstniki) in izobraževalnem (npr. oblikovanje otrokovega odnosa do šole) področju. Vsi mladostniki, ki so poročali o svojih izkušnjah vključevanja v razred, so med dejavniki dobre vključenosti izpostavili dobre odnose s sošolci (npr. da so jim sošolci nudili pomoč). Iz odgovorov staršev, učiteljev in mladostnikov je torej razvidno, da vključevanje otrok s cerebralno paralizo v večinske osnovne šole poteka dobro, a je pri tem posebno pozornost potrebno nameniti različnim dejavnikom – tako tistim, ki so ključni že pred otrokovim vstopom v razred, kot tistim, ki omogočajo aktualno udeležanje socialno-emocionalnih vidikov otrokovega delovanja v razredu oz. povezanost/sprejetost s strani sošolcev.

Učitelji, starši in mladostniki so izpostavili različne težave otrok s cerebralno paralizo pri njihovem izobraževanju; nekatere so bile bolj neposredno povezane s cerebralno paralizo (npr. težave na področju motorike), druge pa so bile bolj posledica primarnih težav, kot so npr. težave na psiho-fizičnem področju (utrujenost, hitrost pri šolskem delu), težave na področju verbalnih sposobnosti (govor, govorni nastopi) in težave na socialno-emocionalnem področju njihovega delovanja (socialni stiki, nesamostojnost, strah pred neuspehom). Največ težav pri šolskem delu so učitelji, starši oz. mladostniki s cerebralno paralizo prepoznali pri matematiki, jezikih in likovni umetnosti.

Tudi drugi avtorji (npr. Brossard-Racine, 2012; Horber idr., 2000; Terzić idr., 2012) poročajo, da imajo mnogi otroci s cerebralno paralizo tako primarne težave z motoričnim delovanjem kot tudi njim pridružene težave, ki se kažejo na različnih področjih (npr. pri čustvovanju). Glede na pridobljene rezultate bi se bilo pri poučevanju otrok s cerebralno paralizo v večinski šoli potrebno usmeriti tako na primarne težave, ki jih s prilagajanjem metod in oblik dela pri otroku lahko nekoliko omilimo, kot tudi na pridružene težave, ki jih lahko celo odpravimo (npr. na socialno-emocionalnem področju). Socialno-emocionalno področje delovanja učencev lahko učitelji in drugi strokovni delavci načrtno spodbujajo z učenjem vzajemnega medsebojnega sprejemanja in spoštovanja, poudarjanjem skrbi za druge in drugim delovanjem, ki omogoča kakovostno (so)bivanje v razredu.

Učitelji, starši oz. mladostniki so ocenili, da so (bili) večinoma (zelo) zadovoljni s sodelovanjem z drugimi strokovnimi delavci, vključenimi v izobraževanje. Primerjava ocen učiteljev in staršev glede sodelovanja z vodstvom šole, specialnim in rehabilitacijskim pedagogom, spremljevalko in "drugimi udeleženci" ni pokazala statistično pomembnih razlik (Mann-Whitney U-preizkus, $p > 0,05$). To je spodbudno, saj je dobro sodelovanje med vključenimi v delo z otrokom pogoj za kakovostno delo z njim (npr. Marentič Požarnik, 2003). Tudi drugi avtorji (npr. Epstein in Henderson, 1992, v: Intihar in Kepec, 2002; Kalin idr., 2009) so poudarili pomen sodelovanja učencev s

strokovnimi delavci, ki prispeva k razvijanju učenčevih učnih in delovnih navad, sodelovanju pri pouku in učni uspešnosti.

Pridobljeni rezultati omogočajo nova spoznanja o izkušnjah šolanja otrok s cerebralno paralizo v večinskih osnovnih šolah, ki so jih podali različni udeleženci. Ta spoznanja lahko pripomorejo k bolj kakovostnemu načrtovanju in izvajanju dela z otroki s cerebralno paralizo, ki upošteva ne le motorični, ampak tudi izobraževalni in socialno-emocionalni vidik izobraževanja. Pri delu z učenci s cerebralno paralizo bi bilo potrebno upoštevati njihove individualne značilnosti, saj se otroci s cerebralno paralizo med seboj precej razlikujejo po svojih posebnostih in zmožnostih.

Raziskavo bi lahko izboljšali tako, da bi vanjo vključili večje število udeležencev, s katerimi bi izvedli intervju, učenci pa bi lahko poročali o aktualnih izkušnjah šolanja in ne le opisali izkušnje "za nazaj". Intervjuje bi lahko opravili tudi z nekaterimi učitelji in starši ter na ta način pridobili več informacij o izkušnjah s šolanjem otrok s cerebralno paralizo.

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